

Developing a model of the experience of individuals who have self-tested as positive for HIV

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Abstract

Self-testing is a new form of HIV testing introduced to the UK in 2015. A key aim of self-testing is to expand access to testing through reducing barriers for individuals at risk of HIV infection. Self-testing has been shown to be highly acceptable to the key populations at risk of HIV in the UK, namely, Black African men and women, and men who have sex with men (MSM). The vast majority of evidence within the self-testing field relates to the acceptability of self-testing for key populations. As the availability of self-testing increases globally it is important to have a psychological understanding of the pre- and post-self-test experiences of individuals who test positive from this form of testing. This study investigated the key psychological processes involved with self-testing in people testing positive for HIV, for example, choosing to self-test, testing positive from a self-test, linking to HIV care, HIV disclosure, adjustment, coping, and adapting to any relationship changes.

The aim of this Grounded Theory (Charmaz, 2014) study was to explore, and create a model of, the experience of individuals who had received a positive self-test result, and a diagnosis of HIV. Seven MSM aged between 25–53 years were recruited via a nationwide charity pilot project which was designed to send out free self-tests, and was advertised via Grindr, Facebook and the charity website.

Five theoretical codes were identified from the semi-structured interviews and subsequent analysis, and are presented in a theoretical model of the experience of individuals who test positive from a self-test:

1. Self-testing as a purposeful choice
2. Reflecting on the self-testing experience
3. Feeling shock and disbelief
4. Coping with HIV
5. Attempting to move forwards as a sexual person

The findings are discussed with regards to future research and the clinical implications for self-testing, and personal reflections are offered.

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1 Introduction

1.1 Overview of the study

Self-testing is a new form of Human Immunodeficiency Virus (HIV) testing introduced to the UK in 2015. This study explored the experience of seven men who have sex with men¹ (MSM) who had self-tested as positive for HIV. To provide a context for the study, data on HIV globally, and in the UK, will be presented alongside information on HIV treatment. This is followed by information about HIV testing in the UK, and some of the known barriers and facilitators to HIV testing.

Self-testing has been proposed to combat some known barriers to HIV testing, such as stress at having to wait for clinic results (Conway et al., 2015), and HIV-related stigma (Knussen, Flowers & McDaid, 2014). There may however, be unique pre- and post-test challenges with this form of testing, for example: testing without professional support, and linking to HIV care following a positive self-test conducted at home. Literature on the potential challenges facing individuals with a diagnosis with HIV will be presented, particularly studies investigating HIV disclosure, adjustment and relationship impact. Finally, the rationale for this study and research aims will be presented.

1.2 HIV

HIV is a virus that impairs the body's immune system, making it harder to fight the organisms that cause disease (World Health Organization, 2017). The HIV virus destroys and impairs the

¹The term MSM will be used for "men who have sex with men" throughout this thesis. MSM refers to sexual activities between men, regardless of how one identifies, whereas the terms "gay", "homosexual", and "bisexual" include sexual activities but may also be seen as a cultural identity.

function of immune cells, making individuals “immunodeficient” (World Health Organization, 2017). Immunodeficiency gradually results in increased susceptibility to infections, cancers and diseases that those with healthy immune systems can fight off (World Health Organization, 2016a). The most advanced stage of HIV infection is Acquired Immunodeficiency Syndrome (AIDS), which is defined by a significantly weakened immune system and the development of certain cancers or infections. HIV can be transmitted through unprotected sexual intercourse, contaminated blood via infusion and needle sharing, or from mother to child during pregnancy, birth or via breast milk (AIDS.gov, 2015).

HIV globally

Globally, HIV continues to be a major public health issue, with 36.7million people living with HIV, mostly in Sub-Saharan Africa (World Health Organization, 2016a). There are however, active worldwide prevention programmes that have helped reduce the annual number of people acquiring HIV. In 2015, 2.1 million people were newly diagnosed with HIV, which is a 35% decline since 2000 (World Health Organization, 2016a). Furthermore, expansion in the availability of antiretroviral therapy (ART) has reduced the global fatality rate from HIV-related causes to 1.1 million per year, 45% fewer than in 2005.

The World Health Organization (WHO) and The Joint United Nation Programme on HIV / AIDS (UNAIDS) believe that much more needs to be done to reach targets to end the AIDS epidemic as a public health threat by 2030 (World Health Organization, 2016a). As such, the “2030 Fast-Track” targets have been set to accelerate the global HIV response to ending the AIDS epidemic. The targets include the UNAIDS 90-90-90 target for 2020: 90% of people living with HIV knowing their status, 90% of the people who know their HIV positive status accessing treatment, and 90% of the people receiving treatment having suppressed viral loads (World Health Organization, 2016a). Viral suppression is when an HIV-infected person reduces their viral load using ART to an undetectable level; this does not indicate a cure and HIV remains in the body, however the likelihood of transmission is low.

To reach the Fast-Track targets it requires that HIV programmes adapt and change to meet needs (World Health Organization, 2015). An example of a key area of change is the need to be innovative with HIV testing. Globally, 40% of people living with HIV are unaware of their HIV-

positive status (World Health Organization, 2016b). This cohort of people need to be reached through focused and novel testing approaches; examples of this include: partner-testing of HIV-positive individuals, community-based testing, and opportunities for individuals to test themselves at home. These testing initiatives can offer HIV testing in community settings outside of health facilities, which can reach diverse communities (World Health Organization, 2016a). These and other forms of HIV testing will be discussed later in the chapter.

HIV in the UK

In 2015, 6095 people (4551 men and 1537 women²) were newly diagnosed with HIV in the UK, which is a similar number to that reported in preceding years (Public Health England, 2016a). Fifty-four percent of these were reported to be gay, bisexual and other MSM.

At the time of writing, it is estimated that 101,200 people are living with HIV in the UK, and of these, 13,500 (13%) are unaware of their infection, and are at risk of unknowingly passing on HIV (Public Health England, 2016a). HIV in the UK remains most prevalent among MSM, and men and women of Black African ethnicity; these are commonly referred to as the “key populations” for targeting interventions that reduce the incidence of onward transmission and increase the testing of HIV (National AIDS Trust, 2017). Public Health England recommends that individuals at high risk of HIV should test regularly (Public Health England, 2016a). Testing guidance issued to MSM is that they should test at least annually, or every three months if having sex with new or casual partners. Cross-sectional surveys of 2409 MSM were conducted across the UK to measure frequency of HIV testing in the last year (McDaid et al., 2016). Overall, 21.2% of respondents reported having taken four tests, and 33.7% reported having taken 2–3 tests, indicating that approximately 54.9% may test at least annually. Conversely, it is recommended that Black African men and women have an HIV test if having condom-less sex with new or casual partners (NICE, 2016).

²Gender not reported for 7 people

1.3 HIV treatment

Currently, there is no cure for HIV. However, with effective ART to control the virus, as well as preventing onward transmission, people with HIV can enjoy healthy lives and a near-normal life expectancy (Public Health England, 2016a). A prompt diagnosis of HIV is crucial in ensuring swift access to ART to achieve a suppressed viral load more quickly, and late diagnosis is the most important predictor of morbidity in individuals diagnosed with HIV (Public Health England, 2016a). The CD4 count is a laboratory test measuring the amount of CD4 T lymphocytes (CD4 cells) in the blood and is an indicator of how well the immune system is working. CD4 count ranges from 500–1500 cells/mm³ in healthy adults; a CD4 count under 200 cells/mm³ is one of the qualifications for a diagnosis of stage 3 infection/AIDS; late diagnosis is described as a CD4 count below 350 cells/mm³ at diagnosis.

ART consists of a combination of antiretroviral drugs that maximally suppress the HIV virus and stop the disease progressing. WHO recommends that anybody diagnosed with HIV is placed onto ART, regardless of CD4 count at the time of diagnosis (World Health Organization, 2017). The “viral load” indicates the amount of HIV copies in the blood. Reaching an “undetectable viral load” is a key goal of ART, usually suggesting that HIV cannot be detected by standard viral load tests (Claymore, 2013). With an undetectable viral load, the risks of onwards transmission of HIV are minimal (Rodger et al., 2016)

1.4 HIV testing

For somebody infected with HIV, testing is the first step in the HIV continuum of care (Hull, Wu & Montaner, 2012). The continuum of care consists of: diagnosis of HIV, linkage with HIV care, engagement with HIV care, prescription of ART, and viral suppression (e.g., undetectable viral load). The purpose of HIV testing, with regards to the continuum of care, is therefore to identify and effectively link individuals with appropriate HIV treatment and support (World Health Organization, 2015). Figure 1.1 compares the 2015 UK care continuum figures against the UNAIDS 90-90-90 targets: 87% of the 101,200 people estimated to be living with HIV in the UK are diagnosed, using effective and varied testing methods; of those diagnosed, 96% received ART; and of those receiving treatment, 94% had a suppressed viral load.

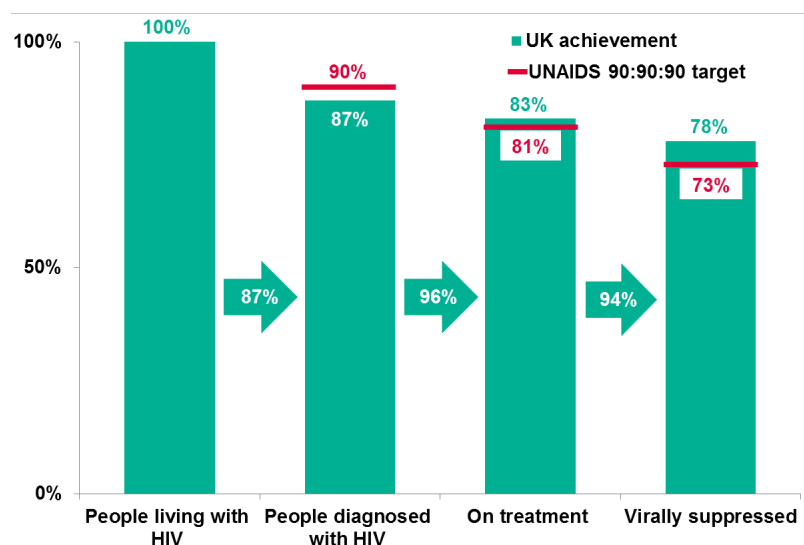


Figure 1.1: Continuum of HIV care in the UK in 2015 against UNAIDS 90-90-90 targets. Public Health England (2016b)

There are several models of HIV testing available, with WHO stipulating that any HIV testing initiative needs to provide testing covering the 5 C's: Consent, Confidentiality, Counselling, Correct test results and Connection (linkage to prevention, care and treatment) (World Health Organization, 2015). Beardsell and Coyle (1996) suggest that HIV testing should be conceptualised as a “macro process” consisting of various subordinate processes. For example, making the initial decision to test, gaining access to a testing site, having HIV counselling, and waiting for the test result, all act as interrelating testing processes. The authors argue that much of the research into HIV testing to date focuses on the discrete aspects of the HIV testing process, rather than as it being a dynamic process with interrelated elements.

Delivering HIV testing

Historically, HIV testing was only offered to people within healthcare facilities when they presented with symptoms that suggested HIV infection, or with behaviour that suggested exposure to HIV (World Health Organization, 2015). However, this approach was often offered too late when people should have started treatment, and so “voluntary counselling and testing” (VCT) was proposed as a new testing format. VCT acts as a form of self-initiated testing that

includes pre- and post-test counselling, and is usually performed within community healthcare facilities and sexual health clinics. VCT acts as an opportunity for individuals to initiate testing themselves and learn their HIV status, as well as to confidentially explore their HIV risks. It is expected that HIV transmission will be lowered through a reduction in high-risk sexual behaviours and access to care and support (World Health Organization, 2015).

Alternatively, provider-initiated testing and counselling (PITC) is HIV testing offered to patients as a standard component of their medical care or for individuals who have an illness that may be indicative of HIV infection (Manirankunda, Loos, Debackaere & Nöstlinger, 2012). This is usually offered as opt-out testing, whereby the patient is notified that a HIV test will be performed unless they decline. In the UK, this form of testing predominantly takes place in primary care settings for individuals living in high HIV prevalence areas, or as part of antenatal screening (NICE, 2016).

Public Health England issued a 2016 report highlighting the different ways that HIV testing is offered in the UK at present (Public Health England, 2016b):

- Universal testing in specialist services: testing in sexual health clinics; prisons; drug and alcohol services.
- Routine testing in areas of high prevalence (>2 per 1000 15–59 year olds): testing in general practice; secondary and emergency care.
- Universal testing where there is a high transmission rate to others: testing at antenatal screening; blood and organ donation.
- Routine testing in high risk groups: testing for sexual partners of those with HIV; individuals with clinical indicator diseases (TB, STIs, Hepatitis B, Hepatitis C); sex workers; transgender people; individuals from a country of high HIV prevalence.
- Testing at home and community settings for high risk groups: targeted testing for Black African communities; gay/bisexual men; targeted self-testing/self-sampling campaigns.

The type of HIV test proposed will differ depending on the environment in which it is offered. Commonly, “point-of-care” (POCT) also known as “rapid” finger prick blood/saliva tests are conducted. The rapid test result can be read by a healthcare professional without the

need for specialised laboratory equipment in less than 30 minutes. Most POCT tests can only detect HIV antibodies, and so once an individual gets a reactive POCT result they still require confirmatory fourth-generation serological testing for diagnosis. Fourth-generation serological tests are blood tests that can detect HIV antibodies and p24 antigens simultaneously. The p24 antigen is a viral protein that is high in the first few weeks after an HIV infection, therefore this type of testing can reduce the time between infection and a positive HIV test result to approximately one month. The time following a potential exposure to HIV infection and an accurate result with testing is called the “window period”; the window period for fourth-generation testing is one month compared to three months for other forms of testing (including those used for self-testing, which will be discussed later in this chapter).

1.5 Barriers and facilitators to HIV testing

It is important to consider the factors that can act as barriers and facilitators to HIV testing for key populations.

HIV risk perception

Accurate assessment of one’s own HIV risk is likely to impact upon HIV testing. Evangelini, Baker, Pady, Jones and Wroe (2016) refer to HIV risk perception as the individual’s belief that they could be HIV positive, which has consequences on whether they subsequently self-initiate or opt in for testing when it is offered. The authors suggest that the Common-Sense Model (Leventhal et al., 1980 cited in Evangelini, Baker et al., 2016) offers a useful framework for understanding HIV risk perception. The Common-Sense Model proposes that different types of information are needed to influence attitudes and actions to a perceived threat to health or wellbeing (Hale, Treharne & Kitas, 2007). The model posits that individuals have “illness perceptions”, that is organised cognitive representations, or beliefs about illness. In the context of HIV testing, individuals may be more likely to test if they believe they could be HIV positive, for example, if they think they have symptoms of HIV that match their own beliefs (illness perceptions) about the disease.

Dowson, Kober, Perry, Fisher and Richardson (2012) conducted semi-structured interviews with seventeen UK-based MSM that had presented late to testing with a CD4 count of less

than 200. Although all participants displayed adequate understanding of HIV transmission and of “high risk” sexual acts, they perceived themselves to be at low risk for contracting HIV. Additionally, the participants in the study were unaware of the consequences of late diagnosis of HIV despite declaring a good general knowledge of HIV. Similar findings were supported by Clifton et al. (2016) in a large British general population survey which highlighted that large proportions of MSM and Black Africans reported sexual risk behaviours (e.g., high frequency of sexual partners, concurrent partners, high frequency of sex with partners without a condom, and not using a condom at first sex with a new partner in the last year). Within these groups, the majority reporting sexual risk behaviours did not perceive themselves to be at risk, and therefore had not tested for HIV. Low risk perception has been noted as a barrier to testing in key populations in several UK studies (Burns, Imrie, Nazroo, Johnson & Fenton, 2007; Burns et al., 2008; Evangeli, Baker et al., 2016; Rice, Delpech, Sadler, Yin & Elford, 2013; Williamson, Dodds, Mercey, Hart & Johnson, 2008).

Psychological factors

There have been numerous psychological factors cited as barriers and facilitators to HIV testing. Evangeli, Pady and Wroe (2016) investigated factors associated with testing as part of a systematic review of the literature. A significant positive relationship was noted in several studies between the perceived benefits of testing and testing behaviour (previous testing or test acceptance on the same day). Furthermore, perceived testing self-efficacy, that is the belief in one’s ability to enact HIV testing, was found in studies with MSM to be positively related to testing and previous testing experiences. Conversely, a negative relationship was noted in three non-UK-based studies between testing fear and previous testing.

Many of the psychological variables measured in the systematic review by Evangeli, Pady and Wroe (2016) are featured in oft-cited health behaviour models such as Theory of Planned Behaviour (Ajzen, 1991) and Health Belief Model (Rosenstock, Strecher & Becker, 1988). The Theory of Planned Behaviour (TPB) suggests that if people evaluate a suggested behaviour as positive, and if they think that significant others want them to perform the behaviour, this will result in higher intention and greater likelihood to perform the behaviour. TPB also introduces the psychological construct of perceived behavioural control, which Ajzen (1991) describes as

a mixture of two dimensions: self-efficacy and controllability. Self-efficacy refers to one's belief in the ability to succeed in a set behaviour, and controllability refers to the internal and external factors that influence behaviour and the extent to which one believes they personally have control over these. The Health Belief Model (Rosenstock et al., 1988) proposes the following theoretical constructs for engagement in health promoting behaviours: *perceived severity* (assessment of the health problem and its consequences); *perceived susceptibility* (risk assessment of developing the health problem); *perceived benefits* (assessment of the value in engaging in the health promoting behaviour); *perceived barriers* (assessment of the obstacles to behaviour change); *cues to action* (internal or external triggers to prompt engagement in the health behaviour); *self-efficacy* (perception of competence to successfully perform the health behaviour). These cognitive models of intentional behaviour may offer useful frameworks for understanding some of the psychological factors influencing HIV testing behaviour.

Fear of HIV was cited as a reason for not testing by MSM living with HIV as part of a qualitative study by Dowson et al. (2012). Only men having a CD4 count below 200 or an AIDS-defining illness at diagnosis were eligible to take part in the UK-based study. The men interviewed all gave descriptions of friends dying of AIDS, and/or had vivid memories of past AIDS advertising campaigns which they partly attributed to negative ongoing views of HIV. MSM in the study argued that health promotion aimed specifically at MSM served to fuel stigma and perpetuated widely-held public beliefs that HIV is a "gay disease", which contributed to their avoidance of testing. Knussen et al. (2014) conducted a study to determine which factors discriminated between three groups of MSM: those that had tested in the previous year, those that had tested one year previously, and those who had never tested. The authors found that fear of a positive HIV test result was greater in those that had never tested. Additionally, the authors noted that due to opt-out HIV testing some participants had been for STI testing but had chosen not to test for HIV at the same time, indicating that fear of a positive HIV test result could be a significant barrier to testing. Moreover, Knussen, Flowers and Church (2004) noted that when gay men with an unknown HIV status had less fear of a positive test result, they had more intention to take a HIV test.

HIV Stigma

Stigma and the effect on HIV prevention, testing and treatment has been well documented (Earnshaw & Chaudoir, 2009). Earnshaw and Chaudoir (2009) indicate that HIV stigma relates to both infected and uninfected people. The authors define stigma as being a devalued attribute in society, which in turn affects the way that people react to the knowledge that they *do not* possess the devalued attribute (i.e., HIV uninfected) or *do* (i.e., HIV infected). In people without HIV, stigma mechanisms such as prejudice, stereotyping and discrimination act in response to the knowledge that there are people living with HIV. In people with HIV, stigma mechanisms such as enacted stigma, internalised stigma, and anticipated stigma derive from the knowledge that they may be subject to other people's negative treatment or moral judgements. Earnshaw and Chaudoir (2009) indicate that it is important to consider these separate processes of HIV stigma when thinking about HIV testing, for example, the extent to which uninfected people may consider themselves members of groups *stereotypically* likely to contract HIV may influence how likely they are to test for HIV. In the migrant African population investigated by Manirankunda, Loos, Alou, Colebunders and Nöstlinger (2009) HIV stigma was linked to culturally-held beliefs about HIV affecting "bad people", and those who were sexually deviant. Avoidance of testing has also been linked to specific stigma-related thoughts, for example, "I am afraid of being treated differently if I take a test" and "I am afraid of being treated differently if I have HIV" in a sample of Black Africans living in the UK (Hickson et al., 2009).

It has been recognised that HIV stigma within the gay community may act as a barrier to HIV testing (Flowers, Knussen, Li & McDaid, 2013; Prost et al., 2007). For example, Prost et al. (2007) attempted to carry out rapid HIV testing in gay clubs which revealed concerns from gay venue owners and service users that to be seen to test would be suggestive of risky sexual behaviour, and would be highly stigmatising. Furthermore, HIV-related stigma from others was cited as a reason for resistance to test in MSM in the UK, with participants highlighting anxieties over taking tests and other people knowing that they were going to test for HIV (Dowson et al., 2012).

Access to HIV testing

In their review of the literature, Bolsewicz, Vallely, Debattista, Whittaker and Fitzgerald (2015) identified several interpersonal factors that can play a role in the uptake of HIV testing in the

UK, Canada and Australia. For example, Deblonde et al. (2010) noted that in a London-based study 40% of respondents indicated that their main reason for testing was on advice given from trusted medical professionals. Conversely, it was noted that perception of poor-quality testing services, including fears around confidentiality, may act as a deterrent to testing.

A study by Lee, Brooks, Bolan and Flynn (2013) investigated the willingness to test for HIV in a sample of MSM, asking participants how willing they would be to test for HIV in eight different testing scenarios. The study identified three factors that the authors suggest affect willingness to test: price, timeliness of results, and location. The study was conducted in the US, where healthcare costs can be significant, so a factor such as price may be more crucial than in the UK, where most forms of HIV testing are free. However, attention should be paid to the latter two points, indicating that timely results and ease of location increase willingness to test. Based on their findings the authors suggested that an HIV test administered at home, with immediate results, was the ideal test option for increasing testing among MSM.

1.6 Home testing for HIV

HIV home testing refers to the performance of a blood or saliva test in the privacy of an individual's home, or any other place that suits the individual. This can be performed using *self-testing*, or *self-sampling*.

Self-testing became available for legal sale in the UK in April 2015, and currently the only test available is BioSURE HIV Self-Test (BioSURE, 2017). A self-test can be ordered from BioSURE's website or online from "freedom-shop", an NHS sexual-health shop and promotion initiative (Home HIV Testing Kits, 2017). The test costs £29.95 for a single use kit. It is not yet clear if the price of the test kit acts as a barrier to accessing self-testing (Frye & Koblin, 2017). Introduction of the self-test for free to high-risk populations has been led by a pilot project run by the Terrence Higgins Trust, a UK-based HIV charity. To self-test, the individual collects a blood spot from a finger prick (or saliva swab available in other countries), runs the rapid test, and the result is available within minutes. If the result is positive, individuals are advised, via information provided by manufacturers, to find a clinic where a fourth-generation serological confirmatory test can be performed, and where they can have access to advice, support and treatment (Krause, Subklew-Sehume, Kenyon & Colebunders, 2013).

Self-sampling differs in that the individual takes a blood spot sample that is then mailed to a laboratory. If the result is negative, the individual receives a text message to their mobile phone. If the result is positive, they receive a telephone call to discuss options and make a referral to relevant healthcare services for confirmatory serological testing and treatment. Globally, the use of self-sampling is uncommon, likely due to the higher demands on laboratory systems. In the UK, self-sampling is not routinely available as part of the NHS. Public Health England launched a self-sampling service in 2015, however this service has not been consistently available across the country (Pebody, 2016). Access to self-sampling is otherwise online via the “freedoms-shop” website (Home Sexual Health Testing Kits, 2017).

WHO (2015) indicates that HIV testing needs to be available in ways that are appropriate and acceptable to key populations to increase the uptake of testing. Research among both men and women has indicated that testing for HIV at home, without a healthcare professional present, is highly acceptable, and is often ranked as the preferred testing method when participants are given an option (Kumwenda et al., 2014; Lippman et al., 2014; Mattioli, Corbelli, Pieralli & Esposti, 2014; Sharma, Stephenson, White & Sullivan, 2014). By giving people opportunities to test for HIV conveniently and discreetly at home there may be an uptake in HIV testing among people not reached by other HIV-testing services, and an opportunity for repeated testing if there is exposure to HIV risk (World Health Organization, 2016b). Furthermore, there is evidence to suggest that self-testing is being accessed by a different group of people to VCT clinic testing and PITC. At present, HIV self-tests for legal commercial sale are only available in the UK, France and the US (Frye & Koblin, 2017). Many other countries have policies in place supporting the implementation of self-testing, however only as part of established pilot and research programs at present (World Health Organization, 2016b). In China, Han et al. (2014) noted that self-testing was associated with a greater number of male anal sex partners than clinic testing, indicating that it may be individuals with particularly high-risk behaviour choosing to self-test. Moreover, research with Brazilian MSM suggests that self-testing also attracts those that may never have tested for HIV (Lippman et al., 2014).

Home testing for conditions other than HIV

In the UK, a range of self-tests for different health conditions have become available to the public within the last few years (Grispen, Ronda, Dinant, de Vries & van der Weijden, 2011; Ryan, Greenfield & Wilson, 2006). It is likely that the need to manage costs within the NHS, as well as the advancement of initiatives such as NHS Direct, have contributed to the development of self-screening of certain conditions (Ryan et al., 2006). A systematic internet search (Ryan et al., 2006) identified 104 unique tests relating to 24 conditions such as specific cancers, chronic conditions and infections. For example, a home self-test has been designed to detect the early stages of dementia or Alzheimer's Disease (Scharre et al., 2010). The Self-Administered Gerocognitive Examination (SAGE) is pen and paper test, evaluating memory, problem-solving and language that can be completed at home within 15 minutes. Users then take the test to their GP who can score the exam to see if further evaluation is needed.

Self-tests do not require the user to communicate with a medical professional before obtaining the test from the internet, or testing at home. Hynes (2013) has cautioned the use of home tests for detecting dementia, and other conditions, however it is recognised that given the apparent popularity of the devices there is a need to develop clear guidelines on their use.

HIV self-testing

The focus of the current study is on HIV self-testing. Self-testing has been shown to have high acceptability as a testing tool for use with key populations (Figueroa, Johnson, Verster & Baggaley, 2015). In a global review of the self-testing literature, Stevens, Vrana, Dlin and Korte (2017) highlighted that the benefits of this form of testing for users include: privacy, ease of use, and convenience. It should be noted that much of the literature reviewed was in studies assessing the acceptability and feasibility of self-testing, there are few studies globally presenting data on individuals having self-tested as positive for HIV. Furthermore, for studies where self-testing is not yet legal there may be some selection bias when individuals are taking part in pilot projects. However, research so far in this emerging field indicates that self-testing helps to facilitate testing, potentially providing access for different people to those who test in health facilities, and empowering those who might otherwise not test (Bavinton et al., 2013; Figueroa et al., 2015; C. Johnson et al., 2014). In addition, the lack of mandatory counselling with self-

testing may help to decrease stigma around testing (Schnall, Carballo-Díez & Larson, 2014). Several studies have explored acceptability and feasibility of self-testing, predominantly with populations where self-testing is not yet available for legal sale. Findings indicate that the key facilitators to the uptake of self-testing are: ease of use and immediate availability of the result (Bilardi et al., 2013; Bowles, 2014; Lee et al., 2013; Nour et al., 2012); increased knowledge of HIV status in resource-limited settings (Cambiano, Mavedzenge & Phillips, 2014); and potential to offer more frequent testing amongst high-risk populations (Carballo-Díez, Frasca, Balan, Ibitoye & Dolezal, 2012; Jamil et al., 2017). Conversely, the known barriers to uptake are: perceptions of the lack of professional support and linkage to care (Bustamante et al., 2016; Katz, Golden, Hughes, Farquhar & Stekler, 2012; Ng et al., 2012; Witzel, Rodger, Burns, Rhodes & Weatherburn, 2016); perceived unreliability of results (Marley et al., 2014); and known cost issues (Frye et al., 2015; Ng et al., 2012; Wood, Ballenger & Stekler, 2014).

Worldwide, evidence into self-testing is emerging. There is currently a large-scale four-year UNAIDS Self-Testing Africa project (STAR) being conducted in Malawi, Zambia and Zimbabwe to distribute and evaluate 750,000 self-testing kits, with the hope of establishing new policy and encouraging new manufacturers to enter the self-testing market (London School of Hygiene & Tropical Medicine, 2017). Additionally, a randomised controlled trial in Australia has evaluated the use of regular self-testing for MSM, indicating that men assigned to receive free self-tests tested twice as frequently than those assigned to facility-based testing as desired, without a decline in the frequency of clinic based testing (Jamil et al., 2017; Jamil et al., 2015).

Self-testing has been met with concern by some (Campbell & Klein, 2006; Richter, Venter & Gray, 2010; Youngs & Hooper, 2015). There are uncertainties around how those that find out their HIV status via self-testing will link with healthcare services, or if self-testing could be used coercively within relationships. It has been suggested, for example, that female sex workers, who are a vulnerable and high risk population, may be at further risk to violence if they are forced to self-test within relationships (Maman et al., 2017; Scott, 2014). Additionally, the user needs to have awareness of the window period during which the self-testing antibody test may show a negative result if an individual is only recently infected (Stevens et al., 2017).

Self-testing in the UK

There is very little European data at present informing interventions into self-testing in the UK. Witzel et al. (2016) conducted focus group discussions with MSM in London, Manchester and Plymouth to understand the acceptability of self-testing in the context of known barriers and facilitators to testing for HIV. The confidentiality and convenience afforded by self-testing was seen to facilitate testing. However, a common cited barrier to using self-testing was the fear of having a positive result without any immediate personal support. Additionally, participants spoke of self-testing having the potential to increase their frequency of testing, but of having concerns relating to separating HIV testing from other forms of STI testing at sexual health clinics. This study forms part of a wider five-year programme (PANTHEON) which aims to determine the most cost-effective HIV-prevention policies to reduce HIV among MSM, with self-testing forming a key part of this process. Relatedly, Flowers et al. (2016) investigated awareness and willingness to use the self-test, particularly in MSM. Focus group data was collected from MSM and other key stakeholders such as NHS staff and community organisations. Willingness to self-test was high in MSM that had never self-tested before, especially in those that were meeting sexual partners online. The NHS/community stakeholders highlighted the overall acceptability of self-testing including its convenience and accessibility, as well as emphasising the low burden to services.

Notably, studies in the UK that have focused on self-testing have largely concentrated on mapping the acceptability of this new form of testing for key populations. To date, there is no published research on the experience of self-testing or any psychological impact on individuals. Witzel et al. (2017, p. 2) indicate that there has been “very little European implementation based evidence and evidence related to patient experience of HIV self-testing”. Moreover, Napierala Mavedzenge, Baggaley and Corbett (2013) identified key gaps in the HIV self-testing literature and proposals for future researchers, including identifying the “secondary harmful effects of self-testing” (e.g., potential for greater psychological trauma), and the “secondary beneficial effects of self-testing” (e.g., potential for personal empowerment, diminished HIV stigma). There may be specific psychological challenges and considerations pre- and post-self-testing that are uniquely different to those faced in other forms of HIV testing.

1.7 Pre- and post-self-test challenges and considerations

Deciding to test at home

Choosing to take a self-test at home may present a unique psychological challenge, certainly as a new form of HIV testing, the psychosocial components of this form of testing are unknown.

Current HIV risk perception, that is, the extent to which one believes that one is HIV positive, may affect the decision to take a self-test. It could be that high HIV-risk perception would increase the likelihood to test at clinic (e.g., concerns about waiting times, access to support and stigma), or it could be that high HIV-risk perception could increase the likelihood for self-testing within a home environment (e.g., concerns about clinic waiting times, stigma). HIV-risk perception has important psychological and behavioural effects (Evangelini, Baker et al., 2016) but it is not currently known how this may relate to self-testing.

Linking with care

HIV testing forms the first step in the HIV continuum of care (Kay, Batey & Mugavero, 2016; Rosen & Fox, 2011). Progression through this continuum is important to ensure that individuals form a relationship with healthcare services and maintain lifelong retention into ART programs. Self-testing presents a unique phenomenon as it is not yet known whether, once tested, individuals will make links to healthcare services. As it stands, with clinic testing there have been identified gaps in care in the first year following a new diagnosis (e.g., no prescription of ART medication, missed clinic visits) (Rana et al., 2015). A case report on self-testing indicated that there was one self-test user who received a positive result and took two months to link with care (Katz et al., 2012). Linkage to care has been highlighted as a concern in implementing self-testing in the UK and across the world (C. Johnson et al., 2014; Napierala Mavedzenge et al., 2013). Understanding how, when, and if individuals link with care has been highlighted as a key global research priority (Napierala Mavedzenge et al., 2013).

HIV disclosure

Disclosure of one's HIV status to significant others is a complex psychosocial challenge for people living with HIV. Disclosure of HIV status has been associated with improved physical

health, psychological well-being and positive health behaviours, including adherence to ART in people newly diagnosed with HIV (Hult, Wrubel, Bränström, Acree & Moskowitz, 2012). Conversely, in a large study ($N = 3258$) of HIV-infected individuals there was no evidence to suggest that non-disclosure was associated with higher prevalence of adverse health outcomes (Daskalopoulou et al., 2016). HIV disclosure can affect people's lives by leaving them vulnerable to social evaluation that could either result in greater social support or greater stigmatisation, depending upon the disclosure confidant. Negative consequences have been associated with HIV disclosure such as: loss of employment, discrimination, rejection and isolation by loved ones (Derlega, Winstead, Greene, Serovich & Elwood, 2004). Though, there is evidence to suggest that disclosure is positively related to social support (R. Smith, Rossetto & Peterson, 2008).

Several models have been described to illustrate the process of HIV disclosure (Chaudoir & Fisher, 2010; Chaudoir, Fisher & Simoni, 2011; Derlega et al., 2004). The Disclosure Processes Model (DPM) (Chaudoir et al., 2011) stipulates that people with HIV face ongoing decisions about HIV disclosure over the course of their lifetime, with different people, at different times, for different reasons. This model posits that there are antecedent processes underlying disclosure behaviour, which affect the disclosure likelihood and subsequent outcome. *Approach goals* are likely to focus on the positive outcomes of disclosure, such as strengthening a personal relationship, and *avoidance goals* focus on avoiding the negative outcomes of disclosure such as social rejection. The DPM predicts that these approach and avoidance goals affect the disclosure, and the outcome. Individuals utilising approach goals are more likely to use effective communication strategies, which elicit positive responses from their confidants and conversely, those with avoidance goals are likely to use less effective communication strategies which may elicit negative or neutral confidant responses.

In a study of HIV disclosure with newly diagnosed men and women, the authors determined that there were distinct differences in whether disclosure was experienced as stressful depending upon how the process was appraised (Hult et al., 2012). Following their qualitative analysis, participants were split into four groups: Stigma Concern, Social Isolation, Strategic Disclosure and Universal Disclosure. In the Stigma Concern group the participants' own internalised stigma, the extent to which people living with HIV endorse negative beliefs as true of themselves, added to the feared response that they received from the confidant. In the Social

Isolation group, participants had commonly experienced early negative experiences of disclosure, which acted as a deterrent from further disclosure. Conversely, in both the Strategic Disclosure and Universal Disclosure groups the participants did not view disclosure as a stressful process but it was often as a way of garnering emotional support, or because they felt as though it would be more difficult not to disclose. This study maps on well to the DPM highlighting that one's own view of disclosure, to that confidant, at that time, is likely to impact upon the disclosure process and subsequent appraisal.

Choosing whom to disclose HIV to is reportedly a challenge. Derlega et al. (2004) highlighted several factors that influence disclosure to intimate partners and close relationships. Their findings suggested that "testing the other's reaction" was endorsed highly as a reason for disclosing more for an intimate partner. Alternatively, the participants endorsed the need for privacy more as a reason for non-disclosure to friends and wider circles. Evidence suggests that MSM disclose more often to friends than family (Serovich, Esbensen & Mason, 2007). Additionally, there are times when disclosure is not an optional behaviour, and individuals with HIV are forced to disclose due to being identifiable at healthcare facilities (French, Greeff, Watson & Doak, 2015). Préau et al. (2015) suggests three distinct patterns of disclosure: direct (i.e., directly telling the target person about their HIV status), indirect (i.e., somebody else telling the target person about their HIV status), and guessed status (i.e., the target person guessing their HIV status). Préau et al. (2015) suggest that to disclose voluntarily, to a chosen target person, is likely to be more beneficial than if any information is disclosed without an individual's consent.

HIV stigma has been related to non-disclosure to sexual partners. Przybyla et al. (2013) found that in their sample of MSM and heterosexual men and women, those that perceived more HIV stigma—as measured on the HIV Stigma Scale (Berger, Ferrans & Lashley, 2001)—were less likely to disclose their status to partners. Conversely, Vu et al. (2012) found that disclosure was more likely amongst those that perceived less HIV stigma. Additionally, internalised HIV stigma may act as a barrier to disclosure, and can be linked to adverse interpersonal consequences in relationships (Overstreet, Earnshaw, Kalichman & Quinn, 2013).

Anxiety related to HIV disclosure is common. Evangeli and Wroe (2017) present a model of HIV disclosure anxiety that draws from known cognitive models of anxiety to explain how anxiety about sharing one's HIV status can be maintained. The model posits that internalised HIV stigma, that is endorsing negative beliefs about oneself as an HIV-positive person, forms a key

distal determinant of HIV disclosure. The model suggests that this internalised stigma is influenced by several contextual aspects: the symbolic context (e.g., community values, community HIV stigma, gender and sexuality representations); material context (e.g., what the individual serves materially to lose/gain from disclosure); relational context (e.g., the level of perceived trust within relationships). The model highlights that disclosure anxiety will occur if the probability of a negative outcome of disclosure is predicted to be high (e.g., “if I tell that person I will be rejected”). Anxiety is then maintained by safety-seeking behaviours such as only disclosing to other known HIV-positive people or attempting to assess potential recipients’ attitudes before disclosure.

Psychological models of adjustment

Adjustment to a diagnosis of HIV is a complex and difficult task. Health behaviour models can be useful in understanding this process, with researchers commonly focusing on the cognitive, affective and behavioural processes that underlie coping and adjustment.

The Common-Sense Model (Baumann, Cameron, Zimmerman & Leventhal, 1989; Sacajiu et al., 2007) describes five conceptual dimensions of illness, namely: identification, cause, timeline, management and consequences. It has been suggested that the “illness representation” of HIV, the way that people make sense of their symptoms to guide their coping actions, has important consequences for effective illness management. For example, in an international, multi-site study of men and women diagnosed with HIV, Reynolds et al. (2009) noted that when there was a perception in participants that “little could be done” it was associated with fewer and less-effective self-care activities. Sacajiu et al. (2007) indicate that the HIV testing context may have a unique effect on the illness representation. The authors split their sample of HIV-positive marginally-housed residents into two groups: the “didn’t suspect and didn’t believe it” group and the “knew but needed proof” group. In the “didn’t suspect and didn’t believe it” group, participants were often tested because of policy requirements, or routine care, and they therefore did not suspect they had HIV prior to testing, struggled to identify a cause of infection, and were likely to attribute HIV to external causes. Moreover, participants in this group expected the prognosis of HIV to be imminent death, thus there was a theme of complete denial of medical needs and management of the diagnosis through “carelessness and chaos”, including

engagement in risky sexual behaviours and drug use. In the “knew but needed proof” group, participants often tested because of knowledge of their risky behaviours, or awareness of loved ones living with HIV, and therefore HIV was spoken of as being part of the participant’s reality before testing. The timeline, management and consequences of the diagnosis differed within this group with some participants experiencing relief and clarity at the diagnosis, and some describing loss and similar experiences of “carelessness and chaos”. As this study was specifically with marginally-housed/homeless participants it limits the generalisability of the findings, however it does highlight how the Common-Sense Model could offer a framework for understanding a relationship between HIV self-testing, illness representation and adjustment.

Coping with a life-threatening illness is central to adjustment. Coping style refers to a person’s preferred coping strategies, and has been related to subsequent distress and quality of life following the diagnosis of a chronic illness (Higgins & Endler, 1995; J. M. Johnson & Endler, 2002). Coping styles and strategies have been described following a diagnosis of HIV, which may influence psychological distress and adjustment to the illness. The Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) provides a framework in which coping is viewed as part of a process that unfolds in response to the demands of a situation that is appraised as stressful. The model suggests that one initially appraises the situation for relevance to their personal wellbeing (primary appraisal) before assessing whether they can cope with the possible benefits or threats (secondary appraisal). Conceivably, many aspects of HIV diagnosis could be deemed as stressful, from the need to adhere to ART, to fear of death, disclosure decisions and interactions with a new and complex medical system. Moskowitz et al. (2012) conducted a meta-analysis to determine the types of coping that are related to psychological wellbeing in people with HIV. The research used the “Ways of Coping” questionnaire by Lazarus and Folkman (1984), which measures eight subscales of coping responses: confrontive, distancing, self-controlling, seeking social support, self-blame, escape/avoidance, planful problem solving, positive reappraisal. The meta-analysis demonstrated that “direct action” (e.g., finding a healthcare provider) and “positive re-appraisal” (e.g., “I have learned something from this experience”) were consistently associated with better outcomes for people coping with HIV. Likewise, Schmitz and Crystal (2000) conducted a longitudinal study with adults and children with HIV, finding that participants that engaged in avoidant coping behaviours, such as escapism or “wishing the problem would go away”, were more likely to experience depression, and

those participants that engaged in more active coping, such as problem-solving and reframing their context were less likely to experience depression. Moreover, it has been seen that emotion-orientated coping strategies, such as “worrying that health might get worse”, were positively related to distress (J. M. Johnson & Endler, 2002). Social support is often cited as providing an important influence in mediating adjustment and coping to an HIV diagnosis (Blaney et al., 1997; Kurdek & Siesky, 1990; McDowell & Serovich, 2007; Peterson, Folkman & Bakeman, 1996; Schmitz & Crystal, 2000). Schmitz and Crystal (2000) suggest that it is the individual’s perceptions of social support that forms the foundation from which coping choices are made. They noted that when participants felt understood and loved following their diagnosis of HIV, their psychological outcomes improved through the effects of the coping strategies they used.

Moss-Morris (2013) has proposed that current psychological models of adjustment offer only partial insight into the challenge of adjustment to illness. Moss-Morris (2013) has suggested a working model with an overarching theory specific to the process of adjustment to a chronic illness. The model proposes that there are background factors (e.g., personality and early life experiences), and social and environmental factors (e.g., support and healthcare) that influence how people will respond to fluctuating illness stressors. Moss-Morris (2013) suggests good adjustment is represented by less distress, less impact on life roles and relationships, good illness management and positive affect. The model emphasises the multi-faceted nature of adjustment, highlighting that individuals can be in adjustment equilibrium and disequilibrium at different times. A strength of this model is that it aims to take a unified approach to adjustment in chronic illness.

Adjustment to a change in sexual behaviour may be one of the unique challenges of living with HIV. Sexual behaviour has been shown to alter following a diagnosis of HIV (Heijman et al., 2012; Steward et al., 2009). Steward et al. (2009) interviewed newly diagnosed MSM, highlighting that the participants were keen to temporarily abstain from sex, seek other HIV positive partners, and reduce their number of sexual partners. Participants attributed these short-term behavioural changes to a “loss of libido” which was seen as a temporary and undesirable state.

On testing positive for HIV, it is recognised that one may feel considerable shock at the diagnosis (Hult, Maurer & Moskowitz, 2009; Imazu, Matsuyama, Takebayashi, Mori & Watabe, 2017). It is important that if individuals diagnosed with HIV experience psychological difficulties, such as anxiety and depression, they receive adequate support. The British HIV As-

sociation (BHIVA) and British Psychological Society (BPS) state that following a diagnosis of HIV individuals should have access to specialised support, and to referral to psychological care (BHIVA & British Psychological Society, 2011). Schmitz and Crystal (2000) highlighted the impact of depression following HIV diagnosis, suggesting that depression could exacerbate the physical impact of the disease process due to the known effects that depression has on the immune system. Therefore, the authors posit that it is of increased importance to understand any processes that may lead to depression within this cohort. Hosek, Lemos, Harper and Telander (2011) presented Project ACCEPT which was aimed at newly-diagnosed adolescents in the US, offering individual and group sessions, with promising effects on depressive symptoms and psychosocial adjustment. Additionally, a recent randomised controlled trial with newly diagnosed participants indicated that a positive affect skills intervention (e.g., one-to-one sessions teaching skills such as mindfulness, goal-setting, positive re-appraisal) offered modest improvements in psychological health (Moskowitz et al., 2017). Adjustment to HIV may be challenging, and depression has been shown to be co-morbid in this population (Do et al., 2014; Sherr, Clucas, Harding, Sibley & Catalan, 2011), however there appear to be few studies in the literature supporting the psychological wellbeing of recently diagnosed adults with HIV.

Relationship impact following an HIV diagnosis

A diagnosis of HIV can have a significant impact in terms of relationship changes. Under UK law it is possible to be prosecuted for recklessly transmitting or knowingly infecting a sexual partner with HIV (Offences Against the Person Act 1861). However, many people living with HIV do not choose to disclose their HIV status to all sexual partners. Przybyla et al. (2013) noted that heterosexual men and women living with HIV were more likely to disclose within relationships than MSM, and that disclosure was more likely in those with longer-term partners than casual partners.

It has been suggested that close personal relationships act as a buffer against the effects of negative life events such as ill health, or a diagnosis of HIV (Harvey & Wenzel, 2002). Hult et al. (2009) suggest that multiple forms of support within relationships including emotional, instrumental and informational are beneficial to people living with HIV. Sachperoglou and Bor (2001) noted that when HIV-positive individuals disclosed to close family members, or close friends,

they tended to experience more positive experiences than negative experiences. Conversely, in their study of the determinants of social support in HIV-positive gay men, Turner, Hays and Coates (1993) suggested that families can be potentially helpful or harmful. Likewise, C. Smith, Cook and Rohleder (2017) found that it was important for individuals with HIV to assess the *quality* of the relationship before disclosing, suggesting that positive qualities in the relationship were associated with positive disclosure outcomes.

1.8 Rationale for the current study

Availability of self-testing is increasing globally. It is therefore important that there is a psychological understanding of the pre- and post-self-test experiences of individuals. Whilst many studies have used quantitative methods to explore the usage, acceptability and feasibility of self-testing, this study is novel in that it is with individuals who have used self-testing, and tested positive from this test. No research to date has explored the psychological processes involved in testing positive from a self-test. Qualitative research has the advantage of exploring different aspects of the pre- and post-self-test experience in depth. This study will investigate the key psychological processes involved with self-testing in individuals testing positive for HIV including: choosing to test, receiving a positive self-test result, HIV disclosure, adjustment, coping, adapting to any relationship changes (e.g., sexual, friends, family, work).

The literature reviewed highlights several key findings which inform this study and provide a rationale for further exploration. The research to date centred on adjustment, disclosure and relationship impact following HIV diagnosis is largely based on clinic testing. This study will address the clear gaps in the literature on self-testing. It hopes to explore the disclosure experiences of individuals that self-test, to add to this gap in the self-testing literature. Additionally, the study will use the psychological models of adjustment to understand the ways that individuals adjust to a diagnosis of HIV following self-testing. Furthermore, this study hopes to understand if and how any relationships (e.g., sexual, friends, family, work) may have been impacted following a diagnosis of HIV from self-testing.

A key concern of the self-testing initiative worldwide has been that of how, when, and if individuals will link to healthcare services, and this study can explore with individuals the psychological process of that decision and any barriers or facilitators experienced. Furthermore,

the rationale of this study is in line with WHO recommendations to conduct qualitative research into the psychological effects of self-testing (Napierala Mavedzenge et al., 2013).

Research aims and questions

The study aims to develop a theoretical model of pre- and post-test experiences in a sample of individuals who test positive from an HIV self-test. The study aims to answer the following research question:

What are the pre- and post-test experiences of individuals including: choosing to take a self-test, receiving a positive self-test result, HIV disclosure, linkage to care, relationship impact, sexual behaviour, adjustment and coping?

2 Method

2.1 Research Design

A cross-sectional qualitative design was used. Grounded Theory (Charmaz, 2014) guided the design, analysis and reporting of the findings from seven semi-structured interviews with MSM who had tested positive from a HIV self-test.

2.2 Inclusion and exclusion criteria

Men and women were deemed eligible to participate in the study if they:

- Had used HIV self-testing, and received a positive result from the test within the last six months, with a minimum post-test duration of one month at interview. This timeframe supported recall validity, allowed for some adjustment to diagnosis and for some post-test experiences, in line with the study research questions. Interviewing participants earlier than one month post-diagnosis might have been ethically problematic, as it could have caused undue distress to participants.
- Had taken a self-test as part of the charity pilot, and it was their first experience of a positive self-test/ diagnosis of HIV.
- Had good spoken English; this was to ensure they could fully engage in a semi-structured interview and to ensure the validity of the analysis.

Anybody demonstrating evidence of significant risk (e.g., self-harm, suicidal ideation or significant low mood) based on the opinion of the Medical Director working with the charity and clinically (acting as field supervisor for this study), was excluded from the study.

2.3 Recruitment source

Participants were recruited via a national HIV charity, which acts as the largest voluntary sector provider of HIV and sexual health services in the UK. The charity provides a range of services such as: long term condition management of HIV; sexual health promotion; and clinical services offering HIV and STI testing to diverse communities. Between June and August 2016, the charity, together with the UK manufacturers of self-test kits, designed and delivered a pilot of national HIV self-testing, providing free self-testing kits to at-risk communities. A core feature of self-testing is the privacy that it offers individuals: people can order and conduct their own test, and healthcare services have no record of this. Furthermore, it is likely that individuals may often attend NHS clinics for confirmatory testing having not told them they have used a self-test beforehand. Therefore, data on self-testers attending clinics is low, or unavailable. This charity self-testing pilot differed in that it offered self-test kits to target at-risk populations, collected data on their positive test results, and had the unique ability to follow those people up.

The service was solely available to those who identified as MSM or Black African men and women. These groups were targeted for participation using methods tailored towards each specific population, primarily using online advertising: for MSM, the charity allocated a marketing budget of £4000 to advertise the self-tests as a pop-up message on Grindr (a mobile-phone-based men-seeking-men dating application). Promotion of self-testing through apps has a high potential to reach untested and high-risk populations and has been used recently to distribute self-tests in the US (Rosengren et al., 2016). Additionally, the charity advertised on Facebook: Facebook allows advertisers to limit an advert to “interest groups”. In this instance the self-testing advert was limited to target men interested in men, restricted by postcode (including postcodes in England, Scotland and Wales). For Black Africans, there was a smaller marketing budget of £500 available, and the targeted advertising was solely through Facebook. The advert was limited to be shown only on pages that may be uniquely “liked” on Facebook by Black Africans living in the UK (e.g., African musicians, recipes).

People ordering the test were asked to provide an address for delivery of the test, their mobile number and an email address to register their HIV test result following testing. Individuals were provided with a secure webpage to inform the charity of their result following self-testing.

Anybody with a positive self-test result was telephoned by the charity's Medical Director to offer support, advice and promote access to care for confirmatory HIV testing. It was at this stage that the current project was suggested to those that had had a positive test.

There were 4975 orders of self-tests made during the pilot programme. People that ordered but were not eligible for the free test were directed to other means of HIV testing (e.g., to a self-sampling service or to the self-testing manufacturer's website). There were 28 positive tests: 12 from Grindr, 8 from Facebook (paid adverts), 4 from Facebook (organic traffic), 4 from the charity website. Out of the 28 positive test results, it was confirmed during the follow-up phone-call that one was a false positive result (i.e. their confirmatory test was negative) and three people had already known their HIV status prior to self-testing. Seven people agreed to be approached by the researcher and were given the participant information sheet by email; all seven completed interviews; and all participants were male. Of the remaining 17 there were no clear reasons for refusal noted.

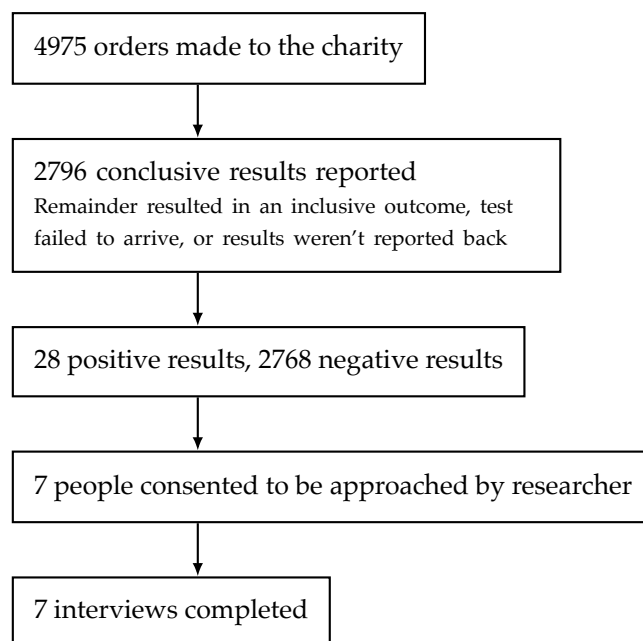


Figure 2.1: Recruitment flow diagram for self-testing pilot

Ethical approval

Full ethical approval for this study was gained from Royal Holloway University of London College Research Ethics Committee (REC). An application was made in the first instance and ethical approval was received in July 2016 (Appendix A). Following this ethical approval, it was clear that an amendment to the ethics application might be beneficial. This would be to broaden the scope of recruitment and include participants living outside of Greater London who would be unable to travel for an interview. This amendment was then made to the application to include Skype interviewing, which was approved in October 2016 (Appendix B).

Ethical considerations

As part of the interviews, participants were asked to talk about personal and potentially emotive experiences. Therefore, it was important to ensure participants gave their informed consent and understood what was asked of them within the research interviews. Participants were informed by participant information sheet (Appendix C), consent form (Appendix D) and follow-up conversation with the researcher of their rights within this research including: withdrawal from the research, stopping the interview, and refusal to answer questions. The consent form also outlined the boundaries of confidentiality, ensuring that participants understood their secure data storage, and the limits of confidentiality if any significant risk was disclosed.

2.4 Choice of methodology

Qualitative methods

This study aimed to understand the experiences of individuals that had tested positive from an HIV self-test. A qualitative methodology was deemed appropriate for this study, particularly as the study aim was to develop a theoretical model within an area that is not currently well understood. Quantitative methods have been commonly used within the field of HIV testing research. However, quantitative methods often do not allow for a detailed exploration of individuals' experiences. As a qualitative methodology, Grounded Theory was considered appropriate to fit the research aim. It allowed the development of a theoretical model, which could help to further understanding of the individual and social processes for this sample.

Grounded Theory

Grounded Theory is a method that offers researchers a systematic means of generating theory from data, that also has the potential to explain, interpret and guide practice (Breckenridge & Jones, 2009). A central focus of Grounded Theory is on uncovering social processes. Crooks (2001) suggests the use of Grounded Theory for exploring integral social relationships and behaviours in groups when there has been little exploration of the contextual factors that affect individual's lives. In the context of HIV self-testing this is particularly applicable because some of the key processes pre- and post-self-testing are social processes (e.g., barriers to testing in the past, decisions regarding disclosure, seeking support from professionals or friends/family, interactions with sexual partners).

Other types of qualitative methods

Other qualitative methods were considered in the early stages of research design, however Grounded Theory was chosen as the most appropriate to meet the research aims. The alternative methods and reasons for not choosing these are outlined below:

Interpretative Phenomenological Analysis (IPA)

IPA is a qualitative approach with an idiographic focus meaning that it aims to offer insights into how an individual, in each context, makes sense of a given phenomenon. IPA is centrally concerned with the meanings that individuals make for themselves from personal experiences (J. A. Smith, Flowers & Larkin, 2009). The in-depth analysis allows for a rich understanding of unique individual experiences. However, the focus on the individual in data-gathering, and analysis, allows for less of an understanding about wider social processes and does not allow for the formation of a theory grounded in experience, as proposed by this study. Given the social relevance of HIV self-testing and pre- and post-test behaviours, Grounded Theory was deemed more fitting for the aims of the present study.

Discourse Analysis (DA)

DA considers the importance of language in the construction of meaning. Starks and Brown Trinidad (2007, p. 1374) suggest that DA is primarily concerned with how "individuals accom-

plish personal, social and political projects through language”, and that it is with careful analysis of language that we can make sense of social norms. This social constructionist viewpoint would lend itself to the wider research questions, however as Grounded Theory adds a more focused exploration of individual experiences and social processes, as well as the formation of a theory, it is more fitting to this study’s aims.

History of Grounded Theory

The publication of Glaser and Strauss’ *The Discovery of Grounded Theory: Strategies for Qualitative Research* (1967) marked the start of Grounded Theory as a method of inductive qualitative inquiry. This book made an important and revolutionary statement in qualitative research, namely that with systematic qualitative approaches researchers could generate theory from their qualitative data. This foremost version of Grounded Theory marries the two founders’ epistemological positions: Glaser intended to create a methodology that would codify qualitative data and “de-mystify the research process” (Charmaz, 2014, p. 9); Strauss in turn emphasised the importance of viewing language as fundamental in understanding emergent processes and social and subjective meanings. The authors have since taken the theory in divergent directions, with Strauss (Strauss & Corbin, 1998) favouring the application of more technical procedures and Glaser remaining more aligned to the original principles of Grounded Theory.

Constructivist Grounded Theory

Following this divergent move in the theory, a constructivist revision of Grounded Theory was formed (Charmaz, 2001). This adopted the inductive, emergent and open-ended approach of the original theory, as well as including some important assumptions about researcher position. The constructivist approach treats research as a social construction, and requires that researchers examine how their privilege and preconceptions may shape the analysis (Charmaz, 2014). The current study adopted a constructivist Grounded Theory methodology for qualitative inquiry and analysis. The rationale for using this is that it fits with the researcher’s own beliefs that one’s position within research needs to be acknowledged, understood and accounted for. Moreover, Charmaz’ version stresses the importance of “flexible guidelines” (Charmaz, 2014), which allows for flexibility within the relative constraints of the DCLinPsy format (e.g., con-

ducting a literature review prior to carrying out interviews). This is in opposition to Glaser and Strauss's (2009) original position that suggested researchers adopted a "purist stance", without conducting a literature review, prior to conducting the research interviews and analysis to avoid any preconceptions influencing the analysis.

Theoretical sampling and theoretical saturation

The inductive emphasis of Grounded Theory allows for the use of theoretical sampling, so that novel material, such as interviews from a new subgroup, is included within the research until theoretical saturation is met (Harper, 2011). Theoretical saturation is the point in the research process whereby the researcher has included novel information and no new data appear. Theoretical sampling is pivotal to building up theoretical insights during the analytical process and is therefore selected for "explicating and refining the emerging theory" (Breckenridge & Jones, 2009, p. 113).

The researcher made considerable attempts to recruit via alternative HIV testing routes to increase sample diversity and to explore the emerging theory. However, this was not possible within the DClinPsy timeframe. There was considerable difficulty in locating people who had tested positive from self-tests outside of the current pilot (e.g., through NHS clinics). Therefore, it was hoped that theoretical saturation would be met with most categories with the current sample size. Additionally, the specificity of the study aim and the constrained inclusion criteria made the study more likely to meet saturation earlier (Charmaz, 2014).

Reflexivity

Charmaz (2014) stresses the importance of reflecting on the researcher's own preconceptions on the data and the research process. The researcher kept a reflective diary from the conception of the research; this was especially useful to facilitate researcher reflexivity during the interview process and during analysis (example in Appendix L).

The researcher is a Trainee Clinical Psychologist. She is a 28-year-old, white heterosexual female without a diagnosis of HIV. It was anticipated that many of the participants would identify as gay (or MSM) due to the inclusion criteria of the self-testing pilot. The researcher has a brother who is gay and therefore has some understanding, through this relationship, of the experiences

of a young gay man living in a city. Participants may have assumed heterosexuality and an HIV-negative status of the researcher; this may have affected their level of willingness to share or to feel understood. Conversely, any perceived differences may have made it easier for participants to share. The researcher straddled a position between representing the charity and the university as a researcher, taking these positions within the interviews may have facilitated open conversation. It was important to reflect upon the similarities and differences between the researcher and the participants, and how these may have impacted upon what was spoken or unspoken in the interviews.

The researcher has a clinical interest in Narrative Therapy (Carr, 1998) and Systemic Therapy (Dallos & Draper, 2010), both of which focus on identifying problems originating in a person's environment, rather than from the individual themselves. Keeping these therapeutic orientations in mind contributed to the way that the researcher understood difficulties associated with HIV, such as stigma and adjustment. The researcher had some knowledge of HIV at the outset of the project, having attended sexual health academic lectures and undertaken a brief volunteering program with the recruiting charity several years before. Furthermore, the researcher has experience of working psychologically with people with long-term conditions (e.g., stroke, visible differences, sickle-cell disease). These experiences helped the researcher understand, through hearing stories, some of the challenges of diagnosis and adjusting to living with a long-term health condition.

2.5 Procedure

Data collection

The data was collected using semi-structured interviews (Drever, 1995). These were audio recorded, with any further observations about the context or setting noted in the reflective diary to support future data analysis.

A mixture of face-to-face interviews and Skype video calling was used. The interviewer style, interview schedule and outcome measures used remained consistent between these two formats. Skype video calls were not video recorded, but audio recordings were taken using the same recorders for both interview formats.

Interviews

A total of seven interviews took place between 27th October and 11th November 2016. Three were face-to-face, and four were using Skype video calling. The face-to-face interviews took place in a private room within University property. For the Skype interviews the participant was asked to find a private and confidential space, and all participants chose somewhere within their home. Interviews lasted between 39 and 67 minutes, with a mean length of 50 minutes.

The interviews were semi-structured to provide enough flexibility to adhere to the research questions, and respond to participants' individual responses during the conversations. Summary statements were used throughout to clarify the information given, and to provide room for elaboration.

Following the interviews, participants were offered an opportunity for a debrief conversation, asking how they had found the experience of taking part in the study. Several of the participants spoke of the importance of reflecting on their experience, as well as taking part in research of this kind. None of the participants left the conversations demonstrating any clear distress.

Interview schedule

The interview schedule (Appendix E) was developed by the researcher and then reviewed, for amendment, by the internal and field supervisors.

It was decided that a chronological approach should be taken to interviewing the participants, which would consider their experiences before taking the self-test, during the test itself, and any post-test experiences. The questions were formed around these three time periods, and the researcher retained structure within a semi-structured interview format by having these time periods in mind throughout.

The interview schedule employed the use of open-ended questions (e.g., "how did you feel about ordering the self-test?") which allowed participants to describe their experience freely in their own words. Specific prompts were suggested (e.g., "were you alone at that time?") which encouraged participants to elaborate on their given answer.

A mock interview with the internal supervisor provided an opportunity to practice using the interview schedule, clarify and refine interview questions, and receive feedback on the in-

interview style.

Adapting the interview schedule

A service user who was taking part in a colleague's HIV-focused research, and was recently diagnosed HIV-positive, reviewed the interview schedule to provide feedback. Due to the recency of the availability of self-testing services in the UK, the service user had not self-tested himself, however he felt able to comment on the interview schedule given experiences of HIV testing, receiving a diagnosis and managing the aftermath of the diagnosis. Ideally, service user consultation would have taken place with service users that had self-tested and efforts were made to recruit somebody who had tested negative from self-testing but, as the self-testing cohort was made up of so few at the time of researching, this was deemed the most suitable option. Some brief questions (Appendix G) were provided to ask about sensitivity of the wording of the questions, and the service user suggested that the interview schedule was appropriate for use.

A feature of the Grounded Theory process is the simultaneous analysis and amendment of the interview structure, if deemed fit. As such, following review of the first five interviews, subsequent prompt questions were added to the interview schedule for the following two interviews. The prompt questions asked participants to consider their thoughts and feelings about testing beforehand, and assess their confidence in managing the consequences of the test result before taking the test (see Appendix F).

Measures

Participants completed a demographics questionnaire to situate the sample, and provide information about their HIV testing history and current medication (Table 2.1). All participants were gay men with a median age at diagnosis of 33 years. There were two participants that would qualify as being late testers ($CD4 < 350$ cells/mm³); all participants had prior experience of HIV testing.

To provide context, and to refer to in the analysis if needed, participants were also asked to complete the "Hospital Anxiety and Depression Scale" (HADS, Table 2.2). HADS is a 14-item scale: 7 of the items relate to depression, 7 to anxiety; it was created as a tool for the detec-

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tion of anxiety and depression in people with physical health problems (Zigmond & Snaith, 1983). HADS has been highlighted as a useful screening tool for depression in HIV populations (Savard, Laberge, Gauthier, Ivers & Bergeron, 1998).

Payment

Participants were offered payment of £10 plus travel expenses (up to £5) for face-to-face interviews as compensation for their time. The Skype participants were offered an online shopping voucher of £10. All participants gave receipt of this payment.

Skype interview set-up

The participants were sent an “interview pack” by email prior to their interview with items for them to complete, sign using “PDF fill & sign” and return by email. The pack contained PDF copies of the participant information sheet, consent form, demographic questionnaire (Appendix H), HADS (Appendix I) and receipt of payment form (Appendix J). All bar one of the participants could use the “PDF fill & sign” to give signed consent to take part in the study. For the one participant who was unable to give signed consent, this participant sent an email to confirm their informed consent to the study.

Table 2.1: Self-reported HIV testing and demographic information

Ppt no.	Age (yrs at interview)	Ethnicity	Relationship status (at interview)	Employment status	UK region	No. home HIV tests taken previously	No. other HIV tests taken previously	CD4 count at diagnosis	Viral load at diagnosis	On ART
P1	25	White British	Single	Unemployed	London and SE	0	Several	280	Undetectable	Yes
P2	32	White British	Single	Employed f/t	East Midlands	5–6	10+	384	Undetectable	Yes
P3	33	White British	Single	Unemployed	East Midlands	0	2	540–550	Unknown	No
P4	53	White British	Single	Long term sick	London and SE	0	2–3	Unknown	11000	Yes
P5	34	Black Caribbean	Single	Employed f/t	London and SE	1 ¹	5	306	47910	Yes
P6	31	White British	Single	Employed f/t	Scotland	0	1	865	Undetectable	Yes
P7	45	White British	In a relationship	Employed	West Midlands	0	1	950	Unknown	No

¹ Previous attempt with self-sampling

Table 2.2: Self-reported Hospital Anxiety and Depression Scale

Participant no.	HADS Anxiety score ¹	HADS Depression score ²
P1	3	10
P2	6	7
P3	7	6
P4	15	7
P5	3	0
P6	12	7
P7	16	14

¹ 0–7 normal anxiety, 8–10 mild anxiety, 11–21 moderate anxiety

² 0–7 normal depression, 8–10 mild depression, 11–21 moderate depression

2.6 Analysis

Transcription

The audio-recorded interviews were transcribed verbatim for the process of coding. Oliver, Serovich and Mason (2005) suggest the use of a “denaturalised” transcription style in which pauses, stutters, non-verbal responses and interview noise are removed, with the view that “within speech are meanings and perceptions that construct our reality” (Oliver et al., 2005 cited in Davidson, 2009, p. 1274). This transcription style is therefore preferred within Grounded Theory studies whereby it is the social meaning of the language used that is of importance rather than the utterances made.

Coding

Charmaz (2014, p. 113) suggests that coding is the “pivotal link between collecting data and developing an emergent theory to explain these data”. It is a process of actively processing and naming the verbal data to decipher what the researcher sees as important, and defining that as a concept. Coding within a Grounded Theory framework involves at least two phases: an *initial coding* phase of naming each word or line, and a *focused phase* of synthesizing these initial codes. This research can then be refined by *theoretical coding* and *diagramming* if the emerging analysis

indicates that it is necessary. Details of how this study approached these phases of coding are outlined below.

First stage: initial coding

During this stage the researcher conducted careful sentence-by-sentence coding on each of the transcribed interviews. Charmaz (2014) suggests that it is important to ask the following questions of the data during this stage:

- “What is this a study of?” (Glaser, 1978 cited in Charmaz, 2014, p. 116)
- What do the data suggest? Pronounce? Leave unsaid?
- From whose point of view?
- “What theoretical category does this specific datum indicate?” (Glaser, 1978 cited in Charmaz, 2014, p. 116)

In-vivo coding, using participants’ own language to describe a concept, ensured that the researcher stuck “close to the data” (Charmaz, 2014). Additionally, Charmaz (2014) describes the importance of “coding for actions”, with codes written in the gerund (e.g., verbs ending in “ing”). This process ensures that codes are grounded in the data and seeks to curb researcher tendency of making theoretical leaps at the first stage of analysis.

At this stage of analysis, the initial codes were verified by the internal supervisor and a peer group consisting of two Trainee Clinical Psychologists also completing Grounded Theory studies. The quality of the coding was checked by a member of this peer group blind coding a transcript, and discussing with the researcher the differences and similarities in the codes used following this. This ensured the researcher retained reflexivity to the data.

Second stage: focused coding

The initial codes provided many possible directions in which to take the analysis. Therefore, the second stage of focused coding involved a concentration on the initial codes that appeared more frequently, or had more significance to the researcher. At this stage Charmaz (2014) suggests that it is important for the researcher to take a critical and measured stance towards the analysis

to avoid pushing analysis towards any preconceived directions. This focused process allowed the researcher to link together initial codes and make phenomena explicit that the participants might not have conceptualised themselves.

Memo writing

Memo writing acts an important part of the Grounded Theory analytic process, with Charmaz (2014, p. 170) suggesting that memo writing “forms an interactive space and a place for exploration and discovery”. Throughout the coding process the researcher wrote electronic memos, reflecting on emerging thoughts about the data. Memo writing helped the researcher to adopt a reflexive stance and consider the importance of emerging concepts. Discussions with the internal supervisor complemented this, ultimately supporting the creation of focused and theoretical codes (memo examples in Appendix K).

Third stage: theoretical coding and diagramming

The final stage of theory-development involved reviewing the focused codes to see how they related to each other. It is through reviewing memos that focused codes are synthesised into theoretical codes, and in turn, the emergent Grounded Theory. Charmaz (2014, p. 218) suggests that a Grounded Theory diagram allows the researcher to see “the relative power, scope and direction of the categories in the analysis, as well as the connections among them”. A coding table displaying the theoretical, focused and initial codes and a diagrammatic representation of the Grounded Theory model is presented in the results section.

2.7 Quality assurance

The research adhered to published guidelines on good practice and quality in qualitative research (Elliott, Fischer & Rennie, 1999):

Owning one’s perspective

The researcher used a reflective diary throughout to remain reflexive on the research process including the researcher’s own thoughts and values about research; extracts included in Ap-

pendix L.

Situating the sample

Demographic information about the participants is shown in Table 2.1, this can help the reader to assess the generalisability and applicability of the findings to other populations.

Grounding in examples

Direct participant quotations were used in memo writing to ground any developing codes. A transcript extract is included in the Appendix (see Appendix M) to show the process of interviewing, and coding.

Providing credibility checks

Credibility was checked using the peer supervision group with two Trainee Clinical Psychologists. Furthermore, the internal supervisor provided comment on interview style, coding and the emergent theoretical model.

Coherence

Coherence was aimed for by naming the theoretical codes appropriately, as well as providing a clear summary of the analysis. The emergent theory was mapped out using a diagram clearly as well as using a narrative description of the model.

Resonating with readers

The coding table and diagram were sent to three participants to ask whether the analysis had captured their experience. They declined to give comment. Resonance was therefore determined by offering the codes for verification by the internal supervisor, given his extensive experience of working with individuals with HIV. This ensured that the researcher did not miss any important themes.

3 Results

The analysis of the data led to five theoretical codes that form the proposed theoretical model. These are shown in Table 3.1. The theoretical codes consist of 13 focused codes, each containing specific properties that were produced at the initial coding stage. A diagrammatic representation of the relationships between the theoretical and focused codes is presented at the end of this chapter.

Quotes from the participants have been used to illustrate codes, and demonstrate how they are grounded in the data. Any identifiable participant information has been removed to ensure confidentiality, and the participants are referred to by their designated participant number (P1 to P7). Reference and links will be made, where appropriate, to the demographic and self-report information given by the participants in Tables 2.1 and 2.2.

Table 3.1: Theoretical codes, focused codes, initial codes

Theoretical codes	Focused codes	Initial codes
1. Self-testing as a purposeful testing choice	1.1 Identifying negative experiences of clinic testing	Difficulty waiting for clinic results in the past
		Worrying about judgement by others at the clinic
		Life and work commitments being a barrier to clinic testing in the past
	1.2 Being ready to self-test	Using self-sampling in the past
		Describing a curiosity to use a self-test
2. Reflecting on the self-test experience	2.1 Feelings before and during the self-test	Putting off doing the self-test once it had arrived
		Feeling anxious whilst doing the self-test
		Practically doing the test was easy
	2.2 Being alone to self-test	Taking the test at home alone
		Questioning decision to do self-test alone
		Advising others not to self-test alone
	2.3 Knowing what to do immediately after self-testing	Knowing the purpose of confirmatory testing and how to get tested
		Returning to a clinic previously tested at

Table continued on next page

Theoretical codes, focused codes, initial codes

Theoretical codes	Focused codes	Initial codes
3. Feeling shock and disbelief	3.1 Feelings of doubt and uncertainty at the self-test result	Questioning the speed of the positive result
		Thinking that there may have been an error made with the test kit
		Likening the experience to a pregnancy scare
		Only believing positive result after the confirmatory test result was back
	3.2 Feeling frustrated that self-testing was not well understood by healthcare systems	Being unable to be seen quickly enough by clinic staff
		Being shocked that professionals had not seen a self-test
	3.3 Being initially distressed at the confirmed HIV diagnosis	Feeling shocked by the diagnosis
		Feeling sad and depressed
		Expressing anger

Table continued on next page

Theoretical codes, focused codes, initial codes

Theoretical codes	Focused codes	Initial codes
4. Coping with HIV	4.1 Describing disclosure anxiety	Finding it hard to initiate disclosure conversations
		Disclosure anxiety due to fear of sexual rejection or stigmatising responses from others
		Recognising that it matters <i>who</i> disclosure conversations are with
	4.2 Recognising the challenges and opportunities of living with HIV	Identifying clinic visits and medication as reminders of HIV
		Seeing adjustment as a process
		Identifying diagnosis as a catalyst for change
5. Attempting to move forwards as a sexual person	4.3 Needing to educate self and others	Educating self and others about HIV
		Learning best through living with HIV
	5.1 Noticing change in the relationship to sex	Choosing not to have sex since diagnosis
		Noticing a change in sexual response since diagnosis
		Having an undetectable viral load positively changing approach to sex
		Gaining an undetectable status as motivation for continuing with drug therapy

3.1 Self-testing as a purposeful testing choice

All the participants identified reasons why they had chosen to self-test, suggesting that this was a purposeful and intentional testing choice. The reasons for choosing to test in this way differed between participants. Some participants indicated that there had been negative experiences of clinic testing in the past propelling them to try another form of HIV testing. Some participants expressed that they felt ready to try a new approach to HIV testing.

Identifying negative experiences of clinic testing

All participants had had at least one clinic testing experience. Five of the participants identified an isolated negative experience of clinic testing, or a feeling that clinic testing had not been suited to them or their lifestyle.

Three participants highlighted that the most challenging aspect of clinic testing was the requirement to wait for the test results, reporting anxious thoughts during this process. Therefore, a clear benefit of self-testing, for these participants, was the instant results available.

You check in, you might have to wait half an hour then you do [...] ¹ the test and, you know, before years ago we didn't have these instant ones, you know, you had to get blood sent off-and then you get it back in a week's time or something. And sometimes that week window was just horrible, limbo. (P1)

So you'd go in, get into it and have your blood test done and you've still gotta wait like 3 days or a week or whatever to get it tested, and the results back. So obviously, you get really anxious waiting for your results. (P5)

For some participants, negative thoughts of clinic testing originated from worries about what others may have been thinking of them. Participants 3 and 5 spoke of concern stemming from thoughts regarding seeing someone they knew at the clinic. For Participant 7, this came from a memory of a past testing experience where he had felt exposed to others' judgements. None of the participants articulated any clear worries about what they imagined others may

¹An ellipsis [...] denotes that a section of the extract has been removed to promote the clarity of the quote. Words placed between square brackets have been added by the researcher so that the extract can be easily understood.

be thinking about them, rather more of a generalised fear of judgement. For these participants, there appeared to be some degree of shame associated with these previous testing experiences.

I did think to myself: “Oh my god, what if I get down there and there’s someone that I knew? Or that I know of?” (P3)

But I don’t think I ever went back again because I just thought it was horrible [...] the person behind the counter was so loud in sort of saying your business and there was a big queue of people behind you, it was so degrading. (P7)

Clinic testing was highlighted as being restrictive due to the participants’ lifestyle, particularly work commitments. For the four participants that had a fulltime work schedule, it was reported that barriers such as opening times and needing to have an advance appointment made it difficult to go regularly for clinic testing. For Participant 2 this acted as one of the main determinants for using the self-test. Of note, this participant had tested most often at home in the past, using self-sampling tests regularly.

Working kind of a normal nine to 5.30 became quite restrictive to be able to go to the clinic to go have a test because, you couldn’t just say: “Ah, you’re only gonna be there for ten minutes” or something like that. It’s quite a long appointment [...] so you’d end up having to take like an afternoon off work to go and get it done. It became quite difficult to do so. Thankfully the [charity] offer, obviously, the postal kit tests. (P2)

Especially working in retail you work different hours and it’s not always sociable or good hours or sometimes if you go to book something they [the clinic] don’t always have that day free when it’s your day off. (P1)

Being ready to self-test

Participants saw the self-testing advert in different online locations. Five of the participants saw the advert whilst using Grindr, one participant saw an advert on Facebook, and one participant saw it advertised on the charity website. Participants described the benefits of HIV testing overall, and the advertising appeared to trigger an intentional enquiry into self-testing specifically. There was no evidence that there was any degree of coercion to self-test within this sample.

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Two participants had home tested for HIV before in the recent past. Participant 2 spoke of using a mixture of finger-prick self-sampling and self-testing (purchased online). He therefore reported feeling very familiar with testing within his home environment, and was using self-sampling regularly. Conversely, Participant 5 had attempted to use self-sampling in the past and had found it challenging to use, so had given up without completing the test. These experiences of self-sampling may have given participants a feeling of being ready to self-test.

[Self-sampling] I've no problems doing at all. I've not got any problems with like blood or anything like that so because I was quite happy to do that and I got to a point where I was doing that every two or three months. (P2)

I tried one which was a prick one and you have to collect blood into a little tube and then send it off [self-sampling]. Well that one was just like too much effort to get it right so I didn't bother to do that. (P5)

Five participants described ordering the self-test due to a desire to know what this form of testing was like. The curiosity to use a self-test was described by Participants 3 and 6 as their main reason for testing in this way. They had not considered that the test would then be positive.

So I, for me, I just got the home testing kit out of curiosity really, to see what it was about and how that worked, and I then found out. (P3)

So, I jumped up, made myself a cup of tea and was blasé, that's how blasé I was about it. I was like: oh, that's cool, go and make a cup of tea, came back in, see how this works, opened up the kit and I was quite excited actually, strangely enough, to see there's kind of a home kit that can tell you whether or not you've got HIV. (P6)

For some participants, the advertising of the self-test as free contributed to them ordering the test at that time. For example, Participant 1 reported that he had been aware of the self-test but had not ordered one due to the cost of ordering online. Cost may have been acting as a significant barrier to testing for this participant, as by the time he self-tested for this study he was classified as a "late tester" ($CD4 < 350$ cells/mm³). Likewise, Participant 2 saw this as a

good opportunity to try this form of testing out for free, having an awareness that it usually cost.

Cos there is a certain test otherwise if you buy it, it costs thirty pounds. Which I know you can't really put a price on your health but I kept thinking "oh thirty pounds like oh its free at the clinic, I've just got to go to the clinic and do it" but because it was free I sort of thought well it's about time I did another test so I ordered it. (P1)

And I kind of thought, actually, you know, why not do it? It's an opportunity to try the free test. (P2)

For two participants, being ready to self-test meant connecting changes in their health to potential symptoms of HIV. Participant 4 highlighted that it was symptoms consistent with HIV, alongside an external cue from his dentist, and the knowledge that he had put himself at sexual risk many times, that confirmed that he felt ready to test for HIV, and that self-testing was the best choice for him.

I had to go to the dentist and the dentist noticed some white spots under my tongue that she wasn't too sure about. So, she took the photos of my mouth [...] things started adding up for me about my sexual life or behaviour or whatever. (P4)

Because I'm not ill that often, although the last couple of years I have been, I've been managed to explain it [...] And this, I just felt, do you know I need to. There was this gut thing that I thought: I need to get myself tested. (P7)

3.2 Reflecting on the self-test experience

All participants could remember the experience of self-testing well. They had all tested at around the same time point, approximately three months prior to the interviews. This theoretical code consists of specific thoughts and feelings about the self-testing experience retrospectively.

Feelings before and during the self-test

Four of the participants described variations of putting off doing the self-test once it had arrived. Participant 1 and 3 described delaying testing over one weekend due to spending time with friends and family, and a feeling that it was not the right time to test. For Participant 1, following spending time with friends he made an attempt to self-test, however delayed for another day due to feeling anxious about a possible positive test result.

I ordered it and I remember it came but the weekend, it came just before the weekend and it was my friends sort of pre-wedding [...] and I was like I'll do it after the weekend [...] You know cos like a couple of times, I went to [...] do it and then I was like nah not gonna actually. I was getting to the pin prick bit and I was like "oooh nah maybe I'll leave it." (P1)

Similarly, Participants 5 and 7 described delays between receiving the test kit and testing. Neither participant reported a specific reason why they had postponed testing once they had received the kit, however, it may have been that testing anxiety contributed. Additionally, Participant 5, who was a late tester when he was diagnosed, reported that he had left the test aside for several months, although the pilot only started in June and he reported testing in July.

Well what happened was it came in and I just basically just threw it to the corner of my room [...] I just kind of left it there or it got moved somewhere and I forgot about it for a couple of months. (P5)

Feelings of apprehension and anxiety were described by four participants, all of whom hadn't self-sampled in the past, when recounting their experience of taking the self-test. Fear and anxiety, for some, was centred around the practicality of taking the test (e.g., pricking the finger), and for others it focused on apprehension regarding the test result.

I was more worried about that bloody pin thing they put in your finger hurting. (P4)

And I think there was some apprehension a bit seeing: oh, what happens if I do get it but then I just forgot about it until, you know (P7)

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Despite delays, and experiences of anxiety during testing, all participants managed to conduct the self-test without any reported difficulties. Furthermore, the ease of the self-testing experience came as a surprise to some participants who imagined that it would be more challenging.

It was easy [laughter] it was my mind just making more out of it. (P4)

So I just literally just grabbed it, it's really easy, just pinprick and then little vial thing sucks up the blood and then it tells you sort of within 10 minutes if its negative or positive. (P1)

Being alone to self-test

All participants took the self-test alone, without support, within their home environment. Deciding where to test, and with whom, was not spoken about as a pre-testing consideration. This may have been due, as Participant 3 described, to some participants not thinking the test would be positive prior to testing. Alternatively, as Participant 1 suggested, testing alone may have been due to having thoughts that the test might be positive, and thinking that one would cope best with this at this home alone.

I: Do you wish there had been somebody there?

No, not really, no. Because [...] in my mind everything is alright, there's not a problem. (P3)

Then obviously, it came back positive and I was able to sort of then deal with it better than if I was at a clinic, I would have probably broke down. Cos I was like oh my god there is all these people around me I don't want them to know and it's probably more pressure for me. (P1)

The only participant that reported considering his testing context beforehand was Participant 4. He questioned taking the test on his own just prior to taking it, before deciding that he would, in fact, test alone.

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Is this a great idea doing this here on my own? [...] Oh, I thought [...] who would I want sitting here with me while I...? Or where would I go? To round someone's house to say... come on let's keep without the drama you're getting no drama. (P4)

Once there was a positive result, some participants questioned why they had tested alone. There were different emotional reactions in response to this. For Participant 7 this made him consider the different choices that other people might have made in his position, compounding feelings of low mood. He reported throughout the interview that he had been feeling low in mood and testing alone had exacerbated his feelings of low mood and experience of depression.

Me partner's where he is [...] me family are where they are. I'm on this boat on me own and I just thought, do you know? Anybody else, they'd do it with other people. So, it was a bit of self-pity, if you like. (P7)

When reflecting on the self-testing experience, five of the participants said they would give advice to others not to self-test alone. This appeared to be, in part, due to feelings of isolation when finding out the positive self-test result alone. Participant 2 highlighted that if future self-testers believe they might have a chance of getting a positive test result, they should test with another person. Likewise, Participant 6 considered the difference it may have made to have someone with him if he had thought he was likely to be HIV positive when testing.

I think if you're that kind of, concerned to the point where you would get a test [...] Having somebody with you, it's not a bad thing. (P2)

See again, if I was concerned that it was gonna come back positive, yes, I probably would have been wanting some kind of a security about me. (P6)

Specifically, participants stressed the importance of having a supportive presence around when self-testing for any future self-testers. This varied from support at the time of testing, to immediately afterwards.

So, if you was to do the test at home it would be maybe just to have someone with you when you do it just for a bit of support. (P5)

They would need themselves a sensible mind or someone else with them to then guide them to the next step, if that makes sense. (P3)

Despite suggesting that any future self-testers should test with another person, it is of note that none of these participants informed anybody that they planned to take a test before self-testing.

Knowing what to do immediately after self-testing

All participants had an awareness of what to do following the self-test to confirm their HIV diagnosis. An awareness of the purpose of confirmatory testing, and where to get a test appeared to originate from different places for different participants. Participant 5 described having a thorough knowledge of HIV testing through seeing information advertised within the gay scene. Participant 7 took his knowledge directly from the information given with the self-testing kit.

Well I kind of know that because basically [...] I'm quite active on the gay scene so I know there's like [name of clinic] and what have you so I already instinctively knew what to do. (P5)

Because obviously in the instructions it says if you come on, if you test positive you need to go and see someone. (P7)

Commonly, participants reported self-testing and then attending a clinic for confirmatory testing within hours. The longest delay reported between self-testing and confirmatory testing was three days (due to testing on a weekend). Four participants returned to a clinic they had previously had sexual health tests at, largely due to the locality of the clinic. Two participants spoke first with their GP, and were then sent for confirmatory testing at a local sexual health clinic. For Participant 4, he made a choice to travel to a clinic far from his home due to fears over confidentiality at his local hospital.

My local hospital I have a family member working there and I wouldn't wanna bump into them, or my details be on a computer file of the clinic I'd attended or anything like that [...] My first thought was just: take it out of the area [...] just go to there [clinic previously tested at] because I've been there before. (P4)

3.3 Feeling shock and disbelief

This theoretical code was derived from the strong emotional responses of participants during self-testing, and immediately afterwards. This included responses to the self-test itself, and the confirmatory testing.

Feelings of doubt and uncertainty at the self-test result

Considerable feelings of doubt and uncertainty came for some participants as soon as they had completed the test. For some participants, they questioned how quickly the positive result had appeared. The self-test instructions explain that the test will take approximately 15 minutes to complete, however, for most, their result appeared far quicker than this. Some participants felt as though they may have made an error with the test kit. For Participant 7 this involved a process of anxious checking and re-checking of the test.

But these 2 lines it says: oh, it'll take 15 minutes. Did it heck? They just went pshoom. [...] When the two lines came up and I kept checking. I kept on: well there's two lines there, there's two lines on the device, there's two lines on the instructions and I kept looking and I thought: well it's gotta be [...] You go through that sort thing and is it quite correct? Have I done it, right? (P7)

Almost immediately two solid lines appeared [...] Like in a blink of an eye. I looked at it with complete disbelief. (P6)

Two participants likened the self-testing experience to a pregnancy scare, describing shock and disbelief at the positive test result.

The scenario in my head is like a typical soap opera, you know, the women's took the pregnancy test and that's come back, you know, positive but she knows she's not been with anyone. (P3)

It was like: I thought well this must be like what a pregnancy test was like and it was just, do you know what I mean? It was just like a joke for me. (P7)

Some participants struggled to believe their positive result until they had received the confirmatory test result back. For one participant, this was compounded by family members suggesting that he had likely made a mistake with the self-testing. For another participant, he felt dismissive of the self-test result until he had it confirmed.

Up until that point I still had it in my head, especially even with sisters and my family that I'd told about the self-test, like my cousin. They were all like that: "You've got to have made a mistake." (P6)

Maybe at the time I was a little bit dismissive and defensive of what the outcome was to be [...] it was like "oh no, that's not me". That's just, that's just wrong but, no it wasn't in the end, obviously. (P3)

Feeling frustrated that self-testing was not well understood by healthcare systems

As mentioned, most participants attended clinic for confirmatory testing within hours. Linking to care for confirmatory testing was generally described as a simple process however for some participants this experience was met with frustration. Some participants described shock and frustration that self-testing was not well understood by some healthcare professionals. For Participant 1 there was an expectation that following self-testing he would be able to be seen quickly at the clinic.

I explained, I've done a self-test kit you know and the result has come back [...] and she was like "oh you need to come back in two hours and you will probably have to wait two hours". And I was like, that's not really good enough when you've had this kind of result. (P1)

Most participants chose to take their self-test with them for the confirmatory testing. Two participants expressed shock that healthcare professionals had never seen a self-test. This may have put these participants in an unwelcome expert position when they were seeking expert support from healthcare professionals.

When I went to the clinic and I showed the guy, the first thing that kind of surprised me is that none of the team there had ever seen one in person. (P2)

I took my kit into the doctors [GP] and I explained to the doctor what happened and he himself had never, ever saw a home test kit. Nor was even aware that they were available. He checked online to see who the manufacturer was and straight away he closed down the window, so he must have seen the approved logo. (P6)

With regards to linking to long term HIV care, five of the participants were on ART medication at the time of the interviews. It had taken varying lengths of time to start medication regimes. Participant 2 reported that starting treatment was a frustrating process for him as he felt that he needed to convince medical staff of his need for ART. Similarly, Participant 7, who was not taking ART at the time of the interviews, reported feeling concerned about this medical decision in the long term. It is worth noting that both participants lived outside of London where HIV prevalence is lower. This may mean that it takes longer to start on treatment.

It's like, I wanna be taking something to fight it off and make me as safe as possible and get to a point where it is undetectable. But to then have consultants and nurses saying: "Oh no, we don't give it to you yet, you're not serious enough case" and it's like, really? Seriously? Is that what you're telling me? (P2)

It worries me and it gets me depressed thinking: Ok, if I am one of these slow progressors or non-starters or whatever and I don't ever need it [ART]. What happens if all of a sudden I do and how quickly does it take a grip of me? (P7)

Being initially distressed at the confirmed HIV diagnosis

Following the confirmatory testing, and thus a diagnosis of HIV, participants reported experiencing a variety of emotional states. Based on the HADS scores at interview, the described emotional states for most participants were temporary. Most commonly participants described a shock reaction to the diagnosis.

[...] at which point I just collapsed. My mind just went complete blank. My head fell, fell like below my knees and I was kind of now just like clutched up on the chair. (P6)

The feeling was pretty much a bit shell-shocked so to speak. (P3)

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Participants also described feeling initially sad or depressed at the confirmed HIV diagnosis. For Participant 4 the feelings of sadness were acute, and for Participant 7 he identified these feelings as being connected to his long-standing depression. Participant 7 also reported some suicidal thoughts following the self-testing experience. He described these thoughts as strong, particularly immediately following self-testing, but without suicidal intent.

And I was sad and I was quite sad and I went out there with me head hung low kind of feeling. (P4)

Depression side of it certainly kicked in, if ever it kicks in and out, I don't know but it was certainly triggered because I thought: do you know, what's the point in me being here? All I've done is... this has been useless. [...] so I'd gone to my darker days where I had been before. (P7)

Participant 6 described feelings of anger and rage on hearing that the self-test had been confirmed, and that he had a diagnosis of HIV. For him, the anger originated from a feeling that his safety had been violated. He considered himself a very sexually safe person, who had taken few sexual risks, and so to find out that he was HIV positive came as a huge shock.

I just freaked out, started kind of punching units and punching my sister away from me [...] And went in complete rage but I kind of I took the time back to try and just compose myself but also work out how can this be possible? (P6)

3.4 Coping with HIV

Following their diagnosis, and in the months that followed, participants described a variety of different experiences and challenges suggesting that they were adapting, adjusting and coping with HIV.

Describing disclosure anxiety

All participants described some form of anxiety about HIV disclosure. Some spoke about the challenges of having disclosure conversations with friends, family, partners and colleagues. For

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example, Participants 2 and 5 reported anxious thoughts in the lead up to disclosure conversations.

Both times I've told groups of family that was the hardest part to do I think. [...] you know there's no going back once you've kind of said it; that's it. You have to then have that whole conversation. (P2)

It's like coming out again basically. It's like that whole putting a plaster on, like you've gotta build yourself up for it and then once you've told it's ok. (P5)

Some participants highlighted that disclosure anxiety came from a fear of sexual rejection, or of receiving a stigmatising response from another person. Participant 5 recounted disclosure conversations he had had with sexual partners, highlighting the fear of sexual rejection that he had experienced. Supporting this, Participant 2 had an example of an occasion whereby he had chosen the timing of when to share with a sexual partner to minimise feared rejection.

And you start out with: "Shit, I need to tell them" and you tell them and then you're like bracing yourself for the what they're gonna be like but yeah, it's always been ok. (P5)

You kind of don't leave it until last but you get to know them a little bit first before you kind of mention it [...] they're not gonna suddenly ignore you all of a sudden and kind of say: "No, I'm not interested after" [...] whereas if you kind of disclose it quite early on it kind of, you know, the conversation ends. (P2)

Some participants described concerns regarding indirect disclosure, that is, somebody they may disclose to telling another person, which may lead to a stigmatising response. Similarly, for Participant 1, fear of stigma from others was his biggest concern, and this affected the disclosure conversations that he could have.

I wouldn't even have approached the thinking of getting with them because I would have to disclose to them and then I dunno who they're gonna tell. (P5)

Someone will find out who I don't know and they'll react a certain way or you know, just negatively towards you. [...] That's it for me, it's almost like a big balloon that

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almost ready to pop and if someone with the stigma needle comes along and pops it I feel like that's just going to be the moment that I then can't cope. (P1)

Participants reported that varying levels of disclosure anxiety were experienced depending on who disclosure conversations were with. As mentioned, disclosure conversations with potential sexual partners were particularly difficult. Some participants also reported that telling close family members could be challenging.

I'll tell you what was hard to tell was my family. I found that the biggest thing. (P4)

I don't want it getting out and them hearing it from other people but I'm not keeping it a secret, I'm just keeping it away from my family. (P5)

Participants described different family set-ups. Two participants lived at home with immediate family, and other participants described family being more separate. For most participants, sharing with family was an important choice that led to support from relationships closest to them.

And it was it was, yeah, a little tricky but actually, my family and all my friends have been really supportive and everything, really understanding. (P2)

Participants 2 and 6 stressed that disclosing to family, though challenging, had been essential in protecting family from the transmission of HIV. Both participants described hypothetical situations whereby they worried they might hurt themselves in their family's presence, and accidentally transmit HIV.

[relaying conversation with family] "Well I'll tell you what, if in 2 years down the line I cut myself and I'm bleeding and you then find out I'm HIV positive, how will you react? And they were like: 'Yeah, I would kill you by then, by that point I would be really angry and upset with you'. I was like: 'Well you can barely get upset with me now coz I'm telling you from day one.'" (P6)

Recognising the challenges and opportunities of living with HIV

All participants spoke of various challenges and opportunities that have arisen for them as a person living with HIV. Five participants highlighted that clinic visits and daily medication

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act as reminders of their HIV status. For some, these reminders did not bother them, and had become part of a new normality. For others, reminders of HIV was more challenging to adjust to.

Other than that [...] my day-to-day life has not really changed. I take a giant pill first thing in the morning and that's kind of it. I have that daily reminder but it's not a big deal. I go, I take my pill and kind of then get on with my day. (P2)

I'll stick it on a bookshelf and just file it away for a bit. Do you know what I mean? I know it's there. I know I've gotta go to the clinic and I think, you know, I think that's how I've sort of got to organise it if you like. (P7)

Two participants mentioned seeing a Psychologist, there was no explicit mention of post-diagnosis counselling from other participants. Adjustment to the HIV diagnosis was understood as being a process. Participants spoke of an emotional journey from immediate diagnosis, to the time of the interview several months later, and onwards into the future as a man living with HIV. Participants identified that there might be specific challenges to deal with as part of this adjustment process.

I'm not as cheery as I used to be but then, it's still early days. I mean things will, you know, things will change, things will get better and then getting back into employment and things like that. (P3)

I mean coz from the moment I found out I tried to like set a plan of like how am I gonna deal with this? And I've kind of stuck to it of like first of all let me just tell my close friends and then I gave myself a few months to adjust to it and get onto medication and for me it's been quite easy to deal with but everyone deals with it differently. (P5)

HIV was spoken of as a catalyst for change in some participants' lives. For Participants 1 and 3, the diagnosis had allowed them to pause in their work, offering them chance to take stock of the job environments they wanted to be in.

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I didn't really ever sort of think I'd re-evaluate my life like as much as I did you know [...] but this time like looking for another job I've said to myself right, I don't care, nothing under 25k. (P1)

Then when I got my diagnosis it kind of confirmed to me that I wasn't actually happy chasing the career that I was chasing [...] So, when I got my diagnosis that kind of gave me a view of what I want in my life. Which essentially was less stress. (P3)

Additionally, for some participants the HIV diagnosis had been an incentive to take a new healthy approach to their bodies and wellbeing. Commonly, this came in the form of exercise regimes, as well as a heightened awareness of any substances that may interact with ART medications.

I'm healthy eating, live the active lifestyle [...] I'm more aware that stuff could happen if I'm not looking after myself. (P5)

It's to the point where, you know, I need to do some sort of exercise. I mean me partner says [...] we're gonna go the gym, we're gonna look at what we're gonna do eating wise and things like that. (P7)

My health, like taking protein drinks, herbs, different nutritions and that that I used to take when I was at the gym, all of that I need to stock up effectively but also the iron and different herbs like mock thistle and things like that. I have to avoid them because it will counteract my medication. (P6)

Needing to educate self and others

To most of the participants the minutiae of living with HIV as a condition was unknown before testing, and immediately after. All the participants spent considerable amounts of time researching HIV, feeling more empowered in knowing their choices regarding medication, and what to communicate to others.

It's like by knowing and really understanding myself, I feel more confident in being able to answer anyone's questions. (P2)

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And tell people, you know, and just make sure they're reassured about and knowing all the information. So that's why it was good knowing all the information as well to then go "oh this is what it's all about it." (P1)

Several participants reported having friends who were HIV positive and using these friends as helpful resources post-diagnosis. Participants spoke of the advice given from friends about when, and who, to disclose to, and of the encouraging presence of friends living full and healthy lives with HIV. Additionally, two participants reported joining charity-run support groups to meet other newly-diagnosed people, which they said was helpful in educating themselves about HIV. Conversely, some participants had experiences of people close to them being ignorant about HIV. Participants reported feeling as though they needed to educate these people about HIV, and they spoke of different ways of approaching this.

His ignorance was just caused by lack of knowledge, rather than a spiteful thing [...] I've just shown him a few leaflets and gone through a few things and just had conversations with him just trying to educate him about it. (P5)

So an afternoon could be set to do a Q&A session [...] I'll try and educate them as much as I can on it and then leave it up to them to ask me questions, rather than just telling them I'm HIV positive and nothing else. Because I believe people need to be educated about it so that's what we done. (P6)

For two participants, it was highlighted that the most important learning about HIV came, not through research, but through living with the condition. Participant 4 reported that he had made several attempts to engage with HIV literature but that ultimately, he would learn most from living day-to-day. This was a message seconded by Participant 7. It is of note that both participants were older than the others.

Again, it's my knowledge of the whole. I mean the amount I was in hospital they gave me hundreds of leaflets, pamphlets all these things and it was just like I might as well have learnt a new language [...] I'm living it I suppose, and finding out what my where I'm at with it, you know. (P4)

I think since all these things have happened [HIV diagnosis, relationship challenges, depression] I think this is the way that I've... I mean, you know, I'm learning every day. (P7)

3.5 Attempting to move forwards as a sexual person

The final theme highlighted that the participants had changed in their attitude and approach towards sex since the HIV diagnosis. Only three of the seven participants were virally suppressed at the time of the interviews.

Noticing change in the relationship to sex

Several of the participants had not had sexual contact since their diagnosis. For Participant 6 this had been a conscious decision due to not wanting to put himself at any further sexual risk. For this participant, there was a high level of anxiety related to sex, and he had found it best to ban himself from sex until he could manage this anxiety. For Participant 3 he felt that he needed more time to adjust to his HIV diagnosis before having sex again, leading to an ambivalent relationship to sex.

Because I'm too worried that I can catch something now off somebody else [...] So, I have, I've kind of put myself on a sex ban at the moment. (P6)

I mean I'm not 100% sure where my way forward is but it's gotta be right and ready to do anything like that. To try and get the HIV out of my mind so to speak. (P3)

Participants reported noticing differences in their sexual responses (e.g., desire, attraction) following their HIV diagnosis. Participants 3 and 4 highlighted that, for them, the level of attraction to potential sexual partners had not changed, but that their relationship to having sex had altered. For Participant 4, he explained that seeking men on the internet had lost its appeal. Conversely, Participant 3 reported that he felt less motivated to have sex now, largely due to feeling pre-occupied with thoughts about HIV.

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I think it has [...] I wouldn't say I've lost interest, I've certainly not but I just it's lost its, the edge, the appeal. That thing, it's kind of, it's still there but it's not there like it used to be, you know. (P4)

Yeah, pretty much the sex drive. I mean the attraction I still think "Oh" You know, he's alright, he looks good and... but to me there's just like I don't need to, I can't be bothered and I think there's just a lot of it that's in my head. (P3)

For Participant 2, it was concerns regarding transmission of HIV that affected feelings of sexual desire, and motivation to have sex.

So, between then and now kind of [...] I've definitely noticed probably like my sexuality has just, not disappeared, but it's kind of one of those things where it's kind of very diminished just because I don't, I didn't really feel comfortable [transmitting HIV to others]. (P2)

It is worth noting that the participants that reported noticing changes in their sexual responses were all single men who were actively seeking sexual partners through Grindr, prior to their diagnosis. However, two of the participants reported continuing to use Grindr despite choosing not to date or have sex, suggesting that the app may offer intimacy, closeness and friendship.

I'm still speaking to guys. I'm still popping on and off Grindr and there's still people I spoke to previously before my diagnosis [...] we used to meet up that I'm keeping in contact with. Slowly just working on it a little bit at a time. (P6)

I still go online and chat and things like that but as far as having sex, oh no. (P4)

Identifying the importance of becoming undetectable

For some participants, the process of going onto ART medication was an important step with regards to feeling more confident, and motivated to have sex again. This was due, in part, to the undetectable status that could be gained from taking ART medication. One participant reported that having an undetectable status made him feel more comfortable in approaching partners for sex. Another participant highlighted that having an undetectable status was an

affirming message to give to potential sexual partners, and he wanted to feel confident about this.

So it's kind of been a little while [having sex] and I think it partly because, for me, I wanted to get to a point where I was on the drug therapy [...] I wanted to get to a point where my viral load was undetectable [...] before I really kind of felt comfortable. (P2)

Especially now that I'm undetectable, I need to be confident and say that I'm undetectable and hopefully they understand what undetectable means and if they don't it's their loss. (P5)

Obtaining and maintaining an undetectable status was highly important to participants when they thought about having sex in the future. Two participants spoke of an undetectable status, and thus the opportunities available to them, as being their motivation for starting and continuing with drug therapy.

It's quite difficult to do initially. Because I wanted to have that undetectable viral load. I obviously knew I needed to get on to therapy as soon as possible. (P2)

I started medication within the month of being diagnosed and then within a month of starting treatment I was undetectable. And that was, that was the one thing that was keeping me going, was knowing that I can get undetectable. (P6)

3.6 Theoretical model of the experiences of individuals who test positive from a self-test

The main aim of this study was to develop a theoretical model of the experiences of individuals who have tested positive from a HIV self-test. Figure 3.1 outlines how the five theoretical codes, and the focused codes that form each of these, relate to present an explanatory model of HIV self-testing. The diagram has been kept intentionally simple, to both capture the experiences of the individuals in this sample, and have the potential to be applicable to other self-testing groups in the future.

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There are two processes active within the theoretical model. The diagram presents the chronological phases of self-testing: pre-test, within test, and post-test. This is indicated by the brackets either side of the model, shown from top to bottom of the diagram. Additionally, the large, grey arrows present, with additional clarity, the process described by participants, as captured in the theoretical codes. For example, the model indicates that “self-testing was a purposeful choice” and that participants could “reflect on their experience of self-testing”, demonstrating that many had felt “shock and disbelief” (at the self-test or the HIV diagnosis). These initial post-test reactions lead to further post-test experiences (e.g., “coping with HIV”, and “moving forwards as a sexual person”), as indicated by the two arrows.

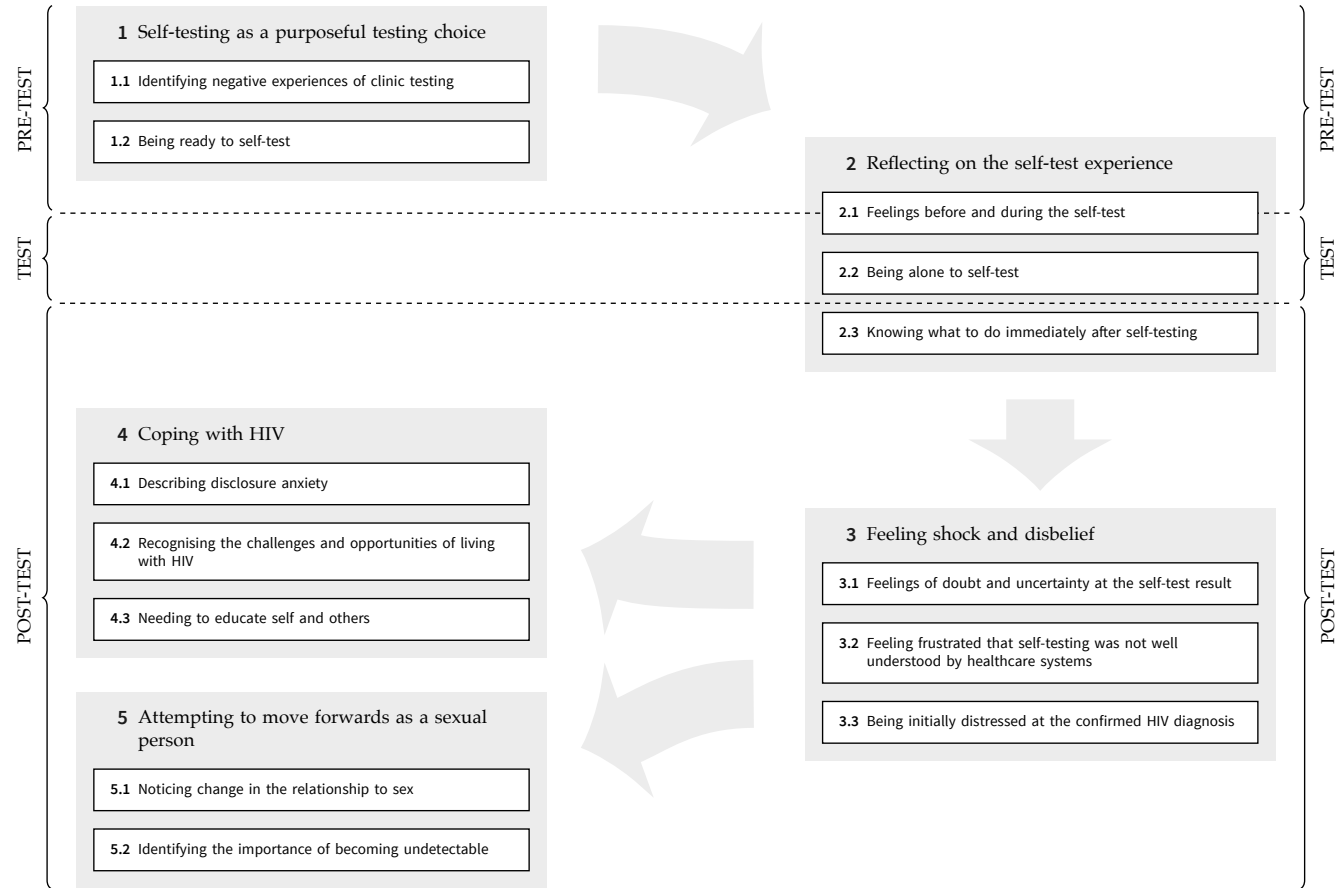


Figure 3.1: Theoretical model of the experiences of individuals who test positive from a self-test

4 Discussion

This study explored the process of self-testing for HIV. Seven MSM were interviewed about their experiences of testing positive from a HIV self-test. A Grounded Theory methodology (Charmaz, 2014) was used to collect and analyse the data with the aim of developing a theoretical model. The study aimed to answer the research question:

What are the pre- and post-test experiences of individuals including: choosing to take a self-test, receiving a positive self-test result, HIV disclosure, linkage to care, relationship impact, sexual behaviour, adjustment and coping?

4.1 Overview of the findings

Overall, a positive experience of using the self-test was described, and participants linked to care quickly. For these participants, there was little evidence of any serious adverse effects of self-testing.

Five theoretical codes were elicited from the data which were suggestive of the social and psychological processes associated with self-testing. These were:

1. Self-testing as a purposeful choice
2. Reflecting on the self-test experience
3. Feeling shock and disbelief
4. Coping with HIV
5. Attempting to move forwards as a sexual person

These theoretical codes will be examined in line with the proposed theoretical model, and the research question, outlining the pre-test, within test and post-test processes associated with self-testing. Relevant literature will be presented, incorporating existing research and psychological theory. The study will be evaluated, alongside discussion of its strengths and limitations. Suggestions for future research and clinical implications will be presented, followed by the researcher's personal reflections on the research process.

4.2 Pre-test processes

In line with the theoretical model, participants reported several pre-test experiences that indicated self-testing was a purposeful testing choice, and an opportunity to try a different form of HIV testing. Some participants described negative experiences of clinic testing in the past. For some, this involved an experience, or perception, of long waits to receive HIV results, or long waiting times in clinic. Although not explicitly stated by participants, there may have been an expectation that they would wait a similarly long time for clinic test results if they tested again now. This finding may have public health relevance as it could be that many people are unaware of rapid (POCT) testing in clinics. Currently, POCT is not routinely offered at all sexual health services. The NICE guidelines for HIV testing (NICE, 2016) suggest that promotional material detailing clinics offering POCT should be widely available, and tailored to the needs of local communities.

For some participants, negative experiences of clinic testing focused around fear of judgement from others, or worries that they might be seen by somebody they knew. This finding supports the qualitative study from Dowson et al. (2012) whereby MSM presented late for HIV testing due to worries about other people knowing that they were going to test for HIV. Relatedly, in the meta-analysis of the psychological processes associated with HIV testing by Evangeli, Pady and Wroe (2016), it was noted that anticipated stigma from others was associated with an absence of HIV testing. For the current sample, there appeared to be some degree of shame associated with previous testing experiences. Gilbert and Procter (2006) describe shame as comprising *external shame* marked by thoughts and feelings that others might view one negatively, and *internal shame* whereby the focus of attention is on the self, with feelings of self-evaluation as inadequate, flawed or bad. Participants' experiences of clinic testing in the past were charac-

terised by external shame; there was no evidence of internal shame or negative self-appraisal. Therefore, it could be that self-testing is a preferred HIV testing choice for individuals who experience more external shame.

Despite some participants expressing concerns about being seen or judged negatively, all participants had tested for HIV in the past, and generally described the perceived benefits of testing. This suggests that there was a mixture of barriers and facilitators to HIV testing occurring at the same time. Testing ambivalence may play a key role in the uptake of testing; one may be aware of testing benefits but be ambivalent due to social barriers or concern over finding a positive result. Ambivalence has been found to undermine choice making in other health contexts such as prenatal screening for Down's Syndrome (Dormandy, Hankins & Marteau, 2006). A key concept in motivational interviewing (MI) is the notion of ambivalence (Miller & Rollnick, 2013). MI interventions have been shown to influence HIV testing uptake in at-risk populations (Alemagno, Stephens, Stephens, Shaffer-King & White, 2009; Foley et al., 2005).

The theoretical model includes the focused code "being ready to self-test", which comprises being curious about self-testing, and wanting to know more about it. The advertising for this pilot was shown in a variety of online locations which may have acted as an external trigger to test. This is in keeping with the Health Belief Model (Rosenstock et al., 1988) that describes that "cues to action" are necessary for prompting engagement in health behaviours. These triggers can be internal such as physiological cues (e.g., pain, on-going symptoms) or external (e.g., media, information from friends or medical professionals). Moreover, two participants described having used self-sampling in the past, suggesting they had acknowledged the perceived benefits of HIV testing as a detection behaviour. The Health Belief Model suggests that they are likely to engage in similar behaviours (i.e., self-testing) to detect the signs of disease (i.e., HIV).

Two participants reported noticing changes in their health that prompted them to self-test. It was these internal physiological cues, which coupled with the external trigger (e.g., prompt to test by online advertising), resulted in self-testing. Additionally, one participant was aware that he had knowingly put himself at risk of HIV. Evangelini, Baker et al. (2016) suggest that the Common-Sense Model can offer a framework for understanding the relationship between HIV risk perception and testing. The model suggests that HIV testing is more likely if there is an awareness of HIV symptoms, or prompts from the environment that match one's own illness perception of HIV. In this instance, the participant was *aware of his increased HIV risk*, was

receiving messages from his dentist which fit his own *illness perception of HIV*, and this prompted him to think about HIV testing, specifically self-testing.

Participants reported that the self-test being free had facilitated them testing. This is consistent with the self-testing literature that suggests that cost of the self-test can act as a barrier to self-testing for individuals. In a user acceptability of self-testing study in the US, Ng et al. (2012) found that only 28% of participants would pay \$15 for a self-test. Furthermore, Lee et al. (2013) determined that willingness to self-test was significantly positively impacted when MSM in the US were offered the choice of a free test. Moreover, when self-testing was offered free as part of a chemist voucher reimbursement pilot it was associated with increasing the identification of new cases of HIV (Marlin et al., 2014). This study also supports the Jamil et al. (2017) RCT that found that when MSM were assigned to receive free self-tests they tested twice as frequently, without a decline in the frequency of clinic based testing. It is of note that the self-test is not usually free in the UK and this may have clinical implications to be discussed later in the chapter. Due to joining a pilot sending out free self-tests, this study can make suggestions on self-testing beyond what is currently available in the UK. Conclusions may be drawn to a context in the future where self-testing could be free/reduced in price.

There were differences in the CD4 count of participants at the time of diagnosis, with two participants being classified as having late diagnoses (< 350 cells/mm³), and one participant with an unknown CD4 count, but a hospital admission on diagnosis, suggesting his immune system was compromised. These three participants lived in London. Public Health England (2016c) data suggests that the median CD4 for diagnoses in London is 484 cells/mm³, with 32% of diagnoses being < 350 cells/mm³. Public Health England data shows that CD4 count on diagnosis is lower outside of London, suggesting that individuals may have HIV longer before they test. However, in this sample it was the participants living in London that self-tested later. It would be interesting to see if this is a trend reflected in a larger sample of people that have self-tested across the UK.

The findings from this study illustrate that there were different reasons why participants chose self-testing, and that it was a purposeful choice. There was no evidence that participants had been coerced into self-testing, in contrast to concerns raised by Scott (2014).

4.3 Within test processes

The theoretical model denotes participants' reflections on the self-testing experience itself. All participants were alone when they self-tested. Several participants gave advice to others not to test alone. Interestingly, none of the participants reported informing anybody that they were planning to take a self-test beforehand. It has been cited that a main benefit of self-testing is the privacy that it offers users (Stevens et al., 2017). However, participants appeared to describe some ambivalence to the privacy that is offered by self-testing, after the event. It may be that with privacy comes a lack of scrutiny from others, but conversely, a lack of support. Notably, participants were reflecting on this retrospectively in the knowledge that they had tested positive, it might be prudent therefore to ask people without a positive test result their opinion on self-testing alone.

Some participants described delays in taking the self-test once it had arrived due to feeling anxious about the possible test result. Additionally, apprehension and anxiety was described by some participants when recounting their experience of taking the self-test itself. For some participants, anxiety focused on being able to practically conduct the test, and others felt anxious about a positive result. Despite reporting anxiety prior to testing, and at the time of testing, all participants took the self-test without requiring support or guidance. Furthermore, many participants commented on the ease of use. This supports self-testing studies highlighting that individuals are able to conduct and interpret a self-test result without guidance (Bowles, 2014; Carballo-Diéguez et al., 2012; Nour et al., 2012).

Some participants described considerable shock at their self-test result, with some questioning the test validity when the result appeared sooner than they had been expecting. Shock has been noted as a usual reaction to a positive HIV result, regardless of the type of HIV test performed (Hult et al., 2009; Imazu et al., 2017). The Common-Sense Model describes how individuals respond and manage health threats (Baumann et al., 1989). A feature of the model is to delineate between the parallel cognitive processing of a health threat (e.g., "What is the threat, what can I do about it?") and the person's regulation of emotional control (e.g., "How do I feel about it, what can I do to make myself feel better about it?"). Furthermore, a key feature of the cognitive route of the model is that individuals hold illness representations or "lay" beliefs about illness. For the participants in this study it is likely that they went through a pro-

cess of seeing the positive self-test result, drawing on their own illness representation of HIV and potentially experiencing this as an immediate health threat (e.g., “Can this test really be correct?”). Participants did not explicitly state what their illness representations of HIV were prior to testing. It may have been that they imagined they would have had symptoms of HIV, or felt different, exacerbating the feeling of shock. Alongside this, it was important that they regulated their emotional experience, to moderate the initial shock reaction, to enable them to make sense of the positive self-test result, and go for confirmatory testing. The Common-Sense Model has been used to offer a theoretical psychological framework in several other testing contexts (Breland, McAndrew, Burns, Leventhal & Leventhal, 2013; Ozakinci, 2005; van Oostrom et al., 2007). For example, in a study of women testing positive for BRCA 1 gene mutations for breast cancer, women experienced increases in general negative affect, breast cancer worries and test-related distress immediately after their test results. The Common-Sense Model was used to understand psychological responses in the context of reaction to health threats (e.g., illness representations of breast cancer), and on-going health behaviours (e.g., breast checks and mammograms).

4.4 Post-test processes

Existing health behaviour models such as the Health Belief Model (Rosenstock et al., 1988), Theory of Planned Behaviour (Ajzen, 1991) and Common-Sense Model (Leventhal et al., 1980 cited in Evangelini, Baker et al., 2016) offer useful insights into the decision-making processes when individuals may choose to test for HIV, or engage in other health-related behaviours. Furthermore, the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), and Moss-Morris’ working model of adjustment to chronic illness (Moss-Morris, 2013), propose ways that individuals may cope with and adjust to a diagnosis of illness. The main contribution of the present theoretical model is that it highlights the process of self-testing from decision making through to coping and adjustment, and contains this within one theoretical model.

A significant concern regarding self-testing has been whether participants will link with care following their self-test (C. Johnson et al., 2014; Napierala Mavedzenge et al., 2013). Entry into the HIV continuum of care begins with diagnosis (Kay et al., 2016) and so the first step following a positive self-test is attending a clinic for confirmatory testing. Participants described

a good awareness of the purpose of confirmatory testing, and all but one participant went for confirmatory testing immediately after the self-test, with most participants returning to a clinic they had tested for HIV or STIs in in the past. This is in contrast to the self-test user quoted in Katz et al. (2012) case report who had a positive self-test and took two months to present for confirmatory testing. The information that participants used to guide this decision came from instructions given with the self-test itself, and from advertising, which one participant described as arising from the “gay scene”. All participants had been for confirmatory testing by the time of the phone call from the charity Medical Director, and this did not act as a prompt to link with care.

Participants described shock and frustration that self-testing was not well understood by healthcare systems. They reported experiences whereby they were the unwitting expert in self-testing amongst healthcare professionals. It is important to note that some clinics and GPs were unaware of self-testing, and the initial response of these services is not what participants had expected following self-testing. Brincks, Feaster, Burns and Mitrani (2010) describe and explore the “powerful others Health Locus of Control” (HLOC) which is a belief that powerful, external others such as medical professionals control one’s health. The idea that individuals endorse beliefs that health professionals control their health is likely to influence feelings of trust in health professionals. The authors examined the influence of HIV on powerful others HLOC, finding that feelings of trust towards medical professionals was not influenced by powerful others HLOC for individuals with HIV. This suggests that for individuals with HIV something beyond HLOC influences how much trust they have in medical professionals. This may be a concept that is important to consider in future exploration of post-self-testing experiences.

The theoretical model outlines participants’ initial distress at the confirmed HIV diagnosis. One participant who described feeling angry immediately following the HIV diagnosis reported that he had not suspected that he would be HIV-positive when he self-tested. The diagnosis then came as a significant shock to him. Conversely, two participants that described feeling sad and low in mood following their diagnosis reported that it was a change in health had made them suspect HIV prior to taking the self-test. This supports the HIV testing study by Sacajiu et al. (2007), with the authors finding that the emotional reactions and immediate coping strategies differed between the “didn’t suspect and didn’t believe it” and the “knew but needed proof” testing groups.

There were differences between participants in their experience of starting on ART. British HIV Association guidelines (Waters, 2016) recommend that ART is offered to all people living with HIV to prevent onwards HIV transmission, even if CD4 is over 500 cells/mm³. It is not clear why these participants were not offered ART swiftly. The two participants not on ART were living outside of London and there could feasibly be some regional differences in awareness of, and adherence to, national guidelines by healthcare providers. Alternatively, one participant who reported not being on ART, also reported long standing depression, which had worsened since his HIV diagnosis. There is evidence to suggest that adherence to ART is challenging, and that depression can affect ART adherence (Tatum & Houston, 2017). The presence of depression for this participant may have influenced his healthcare provider's clinical decision to start him on ART.

"Coping with HIV" forms an integral part of the theoretical model. Participants described challenges and opportunities that had arisen from their diagnosis of HIV. The Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) suggests that coping involves a process of appraisal. The individual makes a primary appraisal to assess the stressful situation for relevance to their wellbeing, and then makes a secondary appraisal to determine whether they can cope with the possible benefits or threat of the situation. The appraisals made influence the coping behaviours chosen. For some participants, there were aspects of HIV diagnosis that were appraised as being more stressful. For example, reminders to take ART medication and attend clinic appointments were, for some participants, harder to cope with. For most participants, the complexity of disclosure decisions was deemed as stressful.

Whilst it is normative in HIV-positive populations to have concerns regarding disclosure, there may be a proportion of individuals who experience a level of anxiety that impacts on their function. All participants described at least one social context in which they had experienced disclosure anxiety, for example telling friends, family, colleagues or sexual partners. The model of disclosure anxiety presented by Evangeli and Wroe (2017) fits with many of the disclosure concerns that participants shared. The model has three components: HIV core beliefs; a trigger event; threat interpretation and HIV disclosure anxiety. It is suggested that internalised HIV stigma, as a core belief, is likely to predispose individuals to disclosure anxiety. All participants described a trigger event, that is an event where HIV disclosure was thought to be wanted or needed. Participants spoke most often about disclosure being triggered before sex.

This then often led the last stage, feelings of disclosure anxiety, as participants feared rejection or stigmatising responses from others. Finally, the model highlights the processes maintaining anxiety (e.g., safety behaviours, avoidance). In this sample, most participants had withdrawn from sex, which may act as a temporary or long-lasting behaviour. This could be evidence of disclosure avoidance, which could serve to maintain disclosure anxiety. Of note, most participants in the sample were single, this may have made it easier to withdraw from sex in the short term than it may do for individuals avoiding disclosure through withdrawal from sex within relationships.

Participants reported making several decisions regarding disclosure, and all participants had shared their status with at least one person. The timing of disclosure conversations was important for some participants, and they reported waiting for the recipient's reaction before sharing. A similar finding was noted in young adults with perinatally-acquired HIV (Greenhalgh, Evangelii, Frize, Foster & Fidler, 2016). Importantly, there was no evidence that participants in this study experienced disclosure anxiety that impacted on function, and they received positive responses from friends, family, colleagues and sexual partners when they chose to disclose.

Social support has been cited as influencing adjustment to HIV (Blaney et al., 1997; Kurdek & Siesky, 1990; McDowell & Serovich, 2007; Peterson et al., 1996; Schmitz & Crystal, 2000). Participants spoke about the different people in their lives that were supportive to them. Sharing their HIV status had been challenging for some participants but it had opened sources of support. This supports Schmitz and Crystal's (2000) study that noted that when participants felt supported and understood by others, their psychological outcomes improved through the coping strategies they used. A longitudinal study of MSM suggested that MSM disclose more frequently to friends than family (Serovich et al., 2007). In this sample, there was no clear trend, with participants reporting disclosure to both family and friends.

Participants' mood was measured using the Hospital Anxiety and Depression Scale (Table 2.2; Zigmond and Snaith, 1983). Using this questionnaire, individual differences in mood were noted. Two participants were identified as having moderate anxiety, one participant with moderate anxiety and depression, and one participant with mild depression. This is higher levels of anxiety and depression than might be expected of a population sample and may be reflective of poor levels of wellbeing in newly diagnosed HIV-positive populations. Additionally, two participants identified long standing anxiety and depression that may have made coping

with HIV more challenging for them. It has been noted that different coping behaviours are employed by individuals with depression following a diagnosis of HIV (Schmitz & Crystal, 2000). This was not evident in the current sample, however future research could explore the coping strategies used following self-testing for individuals with mental health problems. The relatively high proportion of anxiety and depression within this sample suggests that offering psychosocial support to individuals newly diagnosed using self-testing may be beneficial. In terms of post-diagnosis support, there was no explicit mention of post-diagnosis counselling as part of HIV care, however, two participants had seen a Psychologist and two participants had joined charity-run support groups for education about HIV.

According to Moss-Morris (2013) good adjustment to chronic illness involves less distress, less interference / impact on life roles and relationships, good illness management and high positive affect. Overall, participants could be said to be working towards good adjustment in these terms. For example, there was effective illness management through adherence to ART medication, and for most participants, any experience of distress was acute rather than prolonged, at the time of diagnosis. However, as this is a heterogeneous group it may be unhelpful to group the participants together. As mentioned, two participants had experiences of long-term mental health problems and complex social contexts, which may mean that they were experiencing a more complex adjustment to HIV. In line with the Moss-Morris (2013) model, background social and environmental factors (e.g., mental health problems, relationship difficulties) and key critical events (e.g., development of initial symptoms of illness), may interact with HIV-related stressors (e.g., managing an uncertain future), resulting in potential adjustment difficulties.

Several participants described the HIV diagnosis as being an important catalyst for change. For some this was in regards to taking care of their health in general, and for others it meant they could take stock of their career progression. Moss-Morris (2013) suggests that part of successful adjustment comes from a feeling of self-efficacy regarding generic life situations. Therefore, feeling able to change one's health and career context is likely to be indicative of successful adjustment to illness.

Participants spoke of the importance of educating themselves and others about HIV, and research and education formed a key part of participants' coping. This may have facilitated adjustment to HIV by way of maximising autonomy and promoting good illness management (Moss-Morris, 2013). Additionally, participants spoke of the importance of educating friends,

family and colleagues, especially when they had had experiences of others being ignorant about HIV. This supports literature from Gillard and Roark (2013) who noted that adolescents with HIV valued educating others about HIV because education was perceived as important and beneficial to others.

An important post-test concept outlined in the model is “attempting to move forwards as a sexual person”. Participants described that their relationship to sex had changed since their HIV diagnosis, with many of the participants choosing not to have sex, and not wanting to put themselves or others at risk. This has been found in other samples of HIV-positive individuals (Heijman et al., 2012; Luchters et al., 2008). Heijman et al. (2012) followed MSM before and after a diagnosis of HIV to determine sexual behaviours. The authors noted that the risk of having unprotected anal intercourse one year after diagnosis decreased significantly when compared with one year before. Greene, Derlega, Yep and Petronio (2003) comment that, similarly to the current sample, there is often a disruption in sexual relationships, or loss of sexual libido, following a diagnosis of HIV, often linked to concerns about HIV transmission. BHIVA and British Psychological Society (2011) guidance suggests that HIV services provide appropriate and effective support in relation to sex, relationships and HIV transmission. Participants in this sample did not indicate that they had been offered explicit conversations about sex and relationships post-diagnosis.

One’s sexuality describes the whole way that a person expresses themselves as a sexual being (Kaplan, 1979). It describes how important sexual expression is in an individual’s life, how they choose to express that, and any preference they may have towards the type of sexual partner. As mentioned, for participants in this study they appeared to be going through a process of adjusting to a change in their sexuality. Moss-Morris (2013) highlights that successful adjustment comes when chronic illness impacts less on life roles. Participants described a process of attempting to maintain their life role as a sexual person, adapting to make changes they felt comfortable with, in the context of being newly diagnosed with HIV. Furthermore, some participants spoke of continuing to speak with men online which may suggest that there is value in the intimacy and closeness gained from seeking potential partners, even if they are choosing not to have sex.

For many participants becoming undetectable formed the motivation of starting on, and adhering to, ART medications. A consensus statement, endorsed by several leading HIV experts

worldwide, identifies that there is now evidence-based confirmation that a person living with HIV, who is on ART and has achieved an undetectable viral load for at least six months, has a negligible to non-existent risk of HIV transmission (Prevention Access Campaign, 2017). However, the statement suggests that those living with HIV and some healthcare providers are not always aware of the ways that successful treatment, and an undetectable status, can prevent onwards transmission. Moreover, the authors note that some people living with HIV may not be in a position to reach an undetectable status because of factors that limit their access to ART, such as: inadequate healthcare systems; not being ready to start treatment; experiences of stigma, discrimination or poverty.

4.5 Strengths, evaluation and limitations of the current study

Strengths

Witzel et al. (2017) indicate that there has been “very little European implementation based evidence and evidence related to patient experience of HIV self-testing”. Additionally, Napierala Mavedzenge et al. (2013) identified key gaps in the HIV self-testing literature, including identifying the “secondary harmful effects of self-testing” (e.g., potential for greater psychological trauma), and the “secondary beneficial effects of self-testing” (e.g., potential for personal empowerment, diminished HIV stigma). A key strength of this study is that it addresses these identified gaps in the self-testing literature by focussing specifically on the pre- and post-test *experiences* of individuals who have self-tested, and received a positive result.

This study formed part of a unique pilot introducing free self-tests to the UK. This meant that the sample came from across the UK, and Skype video calling was used to good effect so that there were no limitations on access to any participants, regardless of location. A strength of this study was the systematic sampling method used. All 28 individuals with a positive self-test were approached by the field supervisor with a study invitation at least once by telephone.

It is not a specified aim of qualitative research to be widely generalisable (Leung, 2015). Qualitative research can, however, be observed on its “representational generalisation”, that is the extent to which findings can be generalised to populations outside the population of the study (Ritchie, Lewis, Lewis, Nicholls & Ormston, 2013). It is likely that the sample, though

small, is broadly representative of the MSM population living in the UK. The latest figures from the Office for National Statistics (ONS) states that 68.2% of the gay population in the UK were single or never married / civil partnered (Office for National Statistics, 2016). Six out of the seven participants in this sample were single. Additionally, London has the largest percentage of people who identified themselves as gay, lesbian or bisexual (2.6%). In this study, three of the seven participants lived in London. The ONS suggests that this may be associated with young age and greater diversity seen in the capital. In the current study, two participants were from the East Midlands. The ONS statistics identify that 1.5% of people identify as gay / bisexual in this area, fewer than that of London, and some parts of the UK. This may suggest that living in an area without many other MSM reduces the opportunity to normalise HIV testing, which may increase testing anxiety. It could be that for people living in these areas, self-testing holds the most value. This reflects information from BioSURE, the self-testing manufacturer, suggesting that outside of this pilot, 75% of self-test kits are sent to “non-metropolitan” areas (Brady, 2016). Caution should be taken with generalisability, however the age range of the sample (25–54 years) appears to be representative of the newly diagnosed population of HIV-positive men in the UK (Public Health England, 2016c). The PHE data indicates that most frequently, diagnoses are at the age of 25–49 years, with HIV diagnoses being less frequent in younger and older adults.

Evaluation of the present study in relation to quality standards for qualitative research

The research adhered to published guidelines on good practice and quality in qualitative research (Elliott et al., 1999), as stated in the methods chapter. There are four criteria by which Grounded Theory studies are commonly assessed: fit; work; relevance; modifiability (Charmaz, 2014; Glaser & Strauss, 1967). “Fit” refers to codes that emerge from the data, rather than any preconceived codes or categories from existing theory. “Work” is the ability of the theory to explain behaviour in a substantive area, and predict future behaviour. The “relevance” of a theory refers to the theory’s conceptual grounding and focus on a core concern. “Modifiability” comments on the theory’s ability to be continually modified, as new data emerge to produce new categories, properties or dimensions of the theory. More recently, to complement these criteria, Charmaz (2014) has suggested evaluating using the criteria: credibility; originality; resonance;

usefulness. The quality of this research will be evaluated considering these concepts.

This study meets the criteria for relevance and originality in that it was focused on a novel concept with a core concern: exploring individuals' experience testing positive from a HIV self-test. The use of formal and peer group supervision offered validation on the initial coding, coding table and the diagram. This individual and group supervision ensured that the codes were grounded in the interview data, and provides assurance of fit, work and credibility. Moreover, the internal supervisor previously worked clinically with individuals with HIV which helped to ensure resonance. Throughout the interview and analysis process, the emerging theory was continually modified, thus meeting the criteria for modifiability and credibility. The use of researcher memo writing and reflective diary facilitated the analysis process by ensuring that the researcher could trace analytical decisions. The reflective diary was an asset for acknowledging and recording the researcher's assumptions, experiences and relationship to the research to note interactions with the interviews or analysis (Charmaz, 2014). The Grounded Theory has the flexibility to explain the future behaviour of MSM. In this way, the Grounded Theory can be said to demonstrate its usefulness.

Limitations

The response rate was low, which is a limitation of the study. Additionally, it is unknown if the 17 eligible others with a positive self-test who declined the study invitation were systematically different from the seven participants that chose to take part. For example, in the study sample a higher proportion (71%) of participants were from Grindr, whereas in the total sample, 43% were from Grindr. The sample may demonstrate representational generalisation to the MSM population in the UK, however, it does not represent Black African men and women, who constitute the other population at high risk to HIV in the UK. It was recognised that within the pilot the charity sent out significantly fewer self-testing kits to Black African men and women than white MSM, with only 3.4% of the sample identifying as Black African. The charity identified, following this pilot, that they "needed to better understand self-testing in non-MSM communities" (Brady, 2017). The applicability of this study to the self-testing community in the UK may be limited by the results being focused only on MSM. Furthermore, it would have offered a useful test of the "workability" of the Grounded Theory, and widened the scope of this study,

to interview another population of people having had a positive self-test.

With the small sample size, it is likely that not all categories reached theoretical saturation. However, common themes consistently came up across participants to form the Grounded Theory. The aim of this research was focused and specific. Charmaz (2014) suggests that “a small study with modest aims might allow proclaiming saturation early”. Weiner (2007, cited in Charmaz, 2014) suggests that saturation in Grounded Theory is clearly a judgement made by researchers, but takes into account the situation of the research, including constraints such as time and money. With the current project, there were time constraints implicit in the DClinPsy research process, alongside a fixed recruitment opportunity whereby there was limited access to further participants. Recruitment presented a challenge as it is currently difficult to identify who has tested positive from a self-test outside of the remit of a pilot such as this one. It is important to question whether this sample is representative of other self-testers, outside of the pilot. For example, there are features of this self-testing pilot that are different from the self-testing provision currently available in the UK. The self-test was free as part of the pilot which participants stated influenced their choice to self-test. Furthermore, anybody with a positive self-test result was telephoned by the charity’s Medical Director to promote access to care. This had the potential to act as an external prompt to attend clinic for confirmatory testing. As mentioned, this was not the case in the current sample as all participants linked with care without prompting, however it is not known if the other 17 people outside of this study delayed before linking with care.

All participants had been alerted to self-testing through a form of online advertising. This formed an essential part of recruitment for this study, however, it may be that there are differences in the psychological readiness and behaviour of individuals that choose to self-test but are *not* prompted by an online external message. Whilst a lot of HIV testing is externally prompted (e.g., advertising on buses), it may be that this study was limited in its ability to explore the “pre-testing” behavioural choices of individuals.

As the study involved asking questions about participants’ *pre*- and *post*-test experiences it was important that the inclusion criteria stated that participants had recently had a self-test (e.g., within the last six months), but equally, were not too recently tested to be unethical (e.g., less than one month), and questions regarding adjustment were applicable. Participants were generally three months’ post-diagnosis. This may limit the study in that participants were at

the beginning of their journey of adjustment, perhaps using different coping strategies to if they were interviewed six months or one year from self-test and diagnosis.

Four participants were identified on the Hospital Anxiety and Depression Scale (HADS) as having some form of mild-moderate anxiety /depression. It may have been useful to use another questionnaire measure alongside this to decipher the extent to which mood was related to HIV and self-testing in participants. An illness adjustment measure could be appropriate for this use (Evers et al., 2001).

Conducting a literature review prior to interviewing the participants may have influenced the questions that the researcher asked, and the analysis that took place. Charmaz (2014) reflects on the limitations that can come from conducting a literature review prior to commencing interviews. For example, it is acknowledged that the researcher may see the interview data through the “lens of earlier ideas” (Charmaz, 2014). However, Charmaz (2014) also notes that researchers will, generally, engage with material critically in relation to the project. To counter any explicit bias, the researcher made use of a reflective diary to note assumptions, as well as gaps in knowledge, following the literature review.

Gaining feedback from participants on the theoretical model would have contributed to the assessment of whether the theory “works”. Unfortunately, all the participants who were willing to be contacted following the interviews did not reply to emails when offered a chance to comment. This limits how much one can say the theory resonates with the population that it has emerged from.

4.6 Suggestions for future research

The theoretical model outlines five areas that have potential to be explored in further depth. For example, there are several constructs that could be operationalised using quantitative measures, such as: “feelings before and during the test”; “being ready to self-test”; “feelings of doubt and uncertainty at the self-test result”. Attitudes to testing and intention to test have been operationalised in measures used previously (Evangelini, Pady & Wroe, 2016) and could be further used to explore self-testing.

The participants in this sample had all tested for HIV in the past. In a study with MSM in China it was reported that self-testing was reaching individuals that had never tested for HIV

(Qin et al., 2017). It could be hypothesised that individuals who have never tested might choose to self-test to facilitate privacy, and repeat testers might self-test to avoid being seen or judged negatively. Future research should seek to understand if there are differences in the reasons for self-testing, and the self-test experience for first time HIV testers and repeat testers.

Future research should focus on the experience of self-testing with Black African men and women, as they, along with MSM, carry a disproportionate burden of HIV infections in the UK. A qualitative study should be used to focus, in depth, on their experience of self-testing.

This study has suggested that healthcare workers may not be fully aware of self-testing, or how to expedite confirmatory testing or care for those that have self-tested. A future study could explore healthcare workers' knowledge, training and understanding of self-testing. As the continuum of care (Kay et al., 2016) suggests, anybody testing for HIV in any form, requires a lifelong link with HIV care. This is likely to require a good mutual relationship, and understanding.

Many studies have explored the correlates of HIV testing regardless of the type of HIV test, and several studies have suggested that self-testing is a highly acceptable form of HIV testing, particularly for MSM (Figueroa et al., 2015; Stevens et al., 2017; Witzel et al., 2016). In this study participants suggested that they made a purposeful choice to self-test. Future research should build on the current research to understand why people are self-testing, and the social, psychological and practical barriers and facilitators to this. This might help to further facilitate interventions to promote self-testing amongst key populations.

This research suggested that there was regional variation in the CD4 count at time of self-testing, with participants living in London testing later. Further research should map the CD4 count trend as self-testing increases in usage and popularity. It could be hypothesised that the attraction to self-testing, over other forms of available HIV testing, differs depending on where one lives.

Within this study only one of the seven participants was in a relationship. Another potential avenue for future research could be to investigate the experiences of individuals who have self-tested within relationships. For example, a study could look at partner testing using self-testing, status sharing, and disclosure anxiety, within relationships. This compliments research from Carballo-Diéguez et al. (2012) whereby MSM were offered home-tests to use with sexual partners, and recent WHO guidance on self-testing and partner notification (World Health Or-

ganization, 2016b).

Recently, there have been WHO recommendations for the use of pre-exposure prophylaxis (PrEP) to prevent individuals from acquiring HIV when they are at substantial risk, for example if their partner is HIV-positive (World Health Organization, 2017). In the UK, PrEP is not currently available on the NHS, though it is recently available in Scotland and available for private purchase through online pharmaceutical companies (Terrence Higgins Trust, 2017). With the emergence of PrEP in the UK there may be a much larger role for HIV self-testing, as HIV testing is necessary to confirm a HIV negative status, which is a pre-requisite of continuation with PrEP. Future research could explore how individuals that use PrEP may also use self-testing. It is hypothesised that those that are psychologically motivated to manage their HIV risk through PrEP may also be motivated to use self-testing independently. In a recent quantitative study in Kenya, MSM using PrEP were offered the use of self-testing alongside. Participants reported that self-testing was highly acceptable in this context (Ngure et al., 2017). A qualitative study could explore further what the experience of using PrEP and self-testing concurrently is.

4.7 Clinical implications

The clinical implications will be discussed considering how they affect the following groups: professionals involved in HIV testing, treatment and care; mental health professionals; MSM that may self-test; services for MSM.

Clinical implications for professionals involved in HIV testing, treatment and care

Further education and training is needed for sexual health clinics and GPs on self-testing. It may be important to expedite confirmatory testing for those that have self-tested once they arrive for clinic testing, to reduce any further distress following a self-test. This would rely on self-testers identifying themselves clearly on arrival at clinic/GP. Training should consider the shock that individuals may already be experiencing on arrival for confirmatory testing. Though not described by this sample, high levels of emotion (e.g., shock, anger, distress) can affect individuals' information processing skills, and could interact when one is given information about HIV diagnosis or care, regardless of the HIV test type (BHIVA & British Psychological Society, 2011). Additionally, training should consider some of the reasons why an individual may have

chosen to self-test in the first instance. This may be important as this study has suggested that previous negative experiences of clinic testing contributed to decisions to take a self-test. A positive relationship with clinics from the point of diagnosis onwards is crucial for retention into ART programs.

Most participants returned to a clinic that they had previously had some form of testing at in the past (e.g., HIV or STI testing). This was often to do with the location of the clinic, and was sometimes to do with a sense of familiarity. It could be useful to have written information such as leaflets or posters advertising self-testing within the clinic/GP environment, and highlight the clinic's essential role in confirmatory testing. This information should be targeted at the key populations for HIV testing, and would ensure that if individuals choose to self-test later and get a positive result, they would be aware of where to go and how to link easily with care. Linking to care was not a problem in this sample. Additionally, perhaps every person that tests negative for HIV, regardless of the type of HIV test or location of test, should be given information about the range of testing options available to them. This may highlight the accessibility of self-testing as a future testing option.

Being offered a free self-test was noted as a clear facilitator to self-testing for several participants. Currently, outside of pilots such as this one, the cost of a self-test is £29.95. It is not known whether funding will be offered for self-testing to be free or at lower cost for groups at high risk to HIV, on an ongoing basis. Reducing the cost, or having public health funding to keep self-testing free may be likely to facilitate self-testing.

It is recognised that Black Africans in the UK test for HIV less than other populations, and so it is prudent to find ways to effectively advertise and distribute self-testing to these communities.

Clinical implications for mental health professionals

Several participants described disclosure anxiety in relation to sharing their HIV status with friends, family and colleagues, or sexual partners. It is not known if there is parity of guidance from sexual health services for those newly diagnosed with HIV on how to disclose to others. The BHIVA and British Psychological Society guidance on the "Standards of psychological support for adults living with HIV" (BHIVA & British Psychological Society, 2011) state that clini-

cians need to “understand issues relating to confidentiality and disclosure of HIV status”. However, this guidance does not make any suggestions to clinicians about *how* to support recently diagnosed individuals with making disclosure decisions, or having disclosure conversations. Guidance from professionals should help people to understand the reasons why they might choose to share their status with someone, who to tell, how to tell others, and when to reserve the right not to tell others. Additionally, it would be important for clinicians working psychologically with individuals to note the known psychological components of disclosure anxiety such as those seen in Evangeli and Wroe’s (2017) “model of disclosure anxiety”. Awareness of this model, might help clinicians to support individuals in understanding what maintains high levels of anxiety in relation to disclosure.

Despite anxiety about disclosure, this sample could share their HIV status with friends, family, sexual partners and colleagues when they needed to. Furthermore, when they disclosed the response from recipients was good, and they received support. This might be important for professionals to know in working with HIV-positive clients.

It has been recognised that people living with HIV can access their own emotional support when needed from family, friends, partners and other support groups (BHIVA & British Psychological Society, 2011). However, people newly diagnosed with HIV from self-testing may need further psychological support, in line with a stepped care model (BHIVA & British Psychological Society, 2011). The stepped care model describes four levels: information and support; enhanced support; counselling and HIV specific psychological therapy; specialist psychological and mental health intervention. Four participants in this study were identified as having some form of mild-moderate anxiety/depression using the Hospital Anxiety Depression Scale. BHIVA and British Psychological Society (2011) guidelines suggest that specialists providing “level 3 and 4” psychological support should provide training, supervision and CPD for practitioners operating at levels 1 and 2. Clinical Psychologists are well placed to offer this, and can support in the training of sexual health workers and nurses about self-testing and some of the psychological barriers to accessing clinic care. Furthermore, Clinical Psychologists can offer training on providing brief low-intensity interventions, such as motivational interviewing (Miller & Rollnick, 2013) to support adherence to ART, and support around adaptation to living with HIV (Hosek et al., 2011). Lastly, Clinical Psychologists are well positioned to offer specialised HIV focused assessment and interventions. Interventions should be based on expli-

cit theoretical frameworks with an evidence base for psychological issues associated with living with HIV, including anxiety, depression, and psychosexual/relationship problems. Moreover, there may be evidence for the efficacy of offering positive affect skills, such as mindfulness and goal-setting, to individuals to support psychosocial adjustment (Moskowitz et al., 2017).

Clinical implications for MSM that may use self-testing/other forms of HIV testing

Participants in this study universally noted that the self-test was easy to administer and painless, however several said they anticipated that it would not be. It may be that anxiety or fear about the practicalities of self-testing may be acting as a barrier for some people outside of this study. Future information about self-testing targeted at MSM could highlight the ease of use, for example by using statements from previous self-testers to endorse the ease of use. Moreover, several participants suggested that, if they were to give hypothetical advice to others, it would be not to test alone. Information could be provided as part of the self-test kit instructions to report that support from another person at the time of testing, and immediately following a positive test result, has been highlighted from users as something that may be beneficial. This is not currently reflected as part of the instructions for using the self-test or the BioSURE “Frequently Asked Questions” page (BioSURE, 2017).

It may be useful for MSM testing for HIV to know that, for this sample, sharing their HIV status with family, friends, colleagues and sexual partners was positive and was met with supportive responses. Awareness of a variety of responses to HIV disclosure may minimise HIV testing fear, and increase testing uptake.

Some participants in this study referred to previous negative experiences of clinic based testing, including worries around seeing somebody they knew at clinic based testing. Efforts should be made to inform people that HIV testing can be conducted in a variety of settings including: primary care; sexual health clinics near/far from one’s home; home testing options (self-testing/self-sampling). The extent to which one may have exposure to different forms of HIV testing and messages about different testing options may depend on various factors, including location in the UK.

Clinical implications for services for MSM

For participants in this study it appeared that disclosure anxiety did not impact on their overall functioning, as they could disclose to others and garner support when needed. However, sexual relationships were possibly affected, and participants spoke of being unsure how to disclose to new sexual partners. Currently, one has the option to be open about one's HIV status on dating apps such as Grindr, and recently there are filters on the app to allow users to identify their HIV status. Additionally, with filters such as these on Grindr it is possible to indicate an undetectable status, which was highlighted to be important to the participants in this study. There have been concerns raised about these filters and the opportunity to filter out HIV-positive men within dating apps, as well as the significant risk of discrimination for those that do share their HIV status in this way (Garner, 2016). Grindr has recently made a commitment to reduce HIV stigma on the app by reducing the negative, shaming language used within its membership. Critics of the filtering options on Grindr note that eschewing HIV-positive persons via a filter is not an effective way to remain HIV-negative, as one may be taking risks with people they *think* are HIV-negative but, may actually have undiagnosed HIV, or with people who are not open about their HIV status (Garner, 2016; Tharrett, 2016). Conversely, the filters may offer the option for HIV-positive men to choose to have sex only with other HIV-positive men, a strategy known as "sero-sorting". Research from the US, Europe and Australia indicate that 14–44% of HIV-positive MSM may sero-sort (Cassels & Katz, 2013). Alongside the current pilot, Grindr has been used with good effect in the US to promote self-tests, and has demonstrated its potential to reach high risk, and potentially untested populations (Huang, Marlin, Young, Medline & Klausner, 2016; Rosengren et al., 2016). It is of clinical importance to consider the ways that people with HIV are using the application post-diagnosis.

Overall, MSM may need lots of different ways to disclose their HIV status. For some people disclosing on a dating app may be appropriate and helpful, but for another person it may be exposing and lead to discrimination. A person with HIV makes many lifelong choices about disclosure. One way that services for HIV-positive MSM can help people manage these complex decisions may be to give people options and supportive forums to help with sharing their HIV status.

4.8 Personal reflections

I thoroughly enjoyed this research process, from conception to analysis. As a novice in Grounded Theory, I highly valued learning about this way of approaching novel data.

A challenge when interviewing the participants was remaining in the status of “researcher”. My split role as Trainee Clinical Psychologist means that I was conducting the research interviews and analysis whilst working one-to-one with individuals in a therapeutic capacity. Therefore, it was important that I noticed any urges to step into a therapeutic conversation style with participants, for example, to go beyond what the participant had said, or to offer an analytic stance. Nevertheless, I think that my Clinical Psychology training helped me to be alert and mindful to the myriad ways that the participants were describing their contexts.

It was important to reflect on the similarities and differences between the participants and myself. I am a 28-year-old, white, heterosexual woman, without a diagnosis of HIV. I was mindful that when participants spoke with me about aspects of the gay scene, e.g. Grindr, they would be aware that I did not use the app myself. This may have facilitated an open and honest dialogue. Conversely, some participants may have found this an impediment to my understanding of their situation. Additionally, having conversations with the participants about their sex lives and sexual choices felt important for the research, especially in the context of a recent HIV diagnosis. However, I was aware that being a straight woman may have meant that participants were less able to talk about sex than they would have been with another researcher, for example, somebody they thought may have been a gay man. Dwyer and Buckle (2009) acknowledge that there are strengths to being an “insider” researcher, that is, one gathering data on a phenomenon one has personal knowledge about. However, they also propose that, “holding membership in a group does not denote complete sameness within that group. Likewise, not being a member of a group does not denote complete difference”. I noted that, despite any differences between myself and the participants they were all open and willing to talk about their unique experiences of self-testing with me.

I felt extremely privileged to be privy to the conversations that I had with all participants, particularly as several participants said that they had chosen to tell only a few people about their self-testing experience and HIV status. I spoke openly with some participants about shame and stigma, and I was curious about whether they thought that I too may be judging them. I

attempted to take a non-judgemental stance in my interview style, often choosing to reflect what they had said, and I did not want to be an additional source of shame.

Using Skype to conduct video calls offered an opportunity to interview participants across the country. However, prior to this experience, I had only conducted interviews (clinical or research) face to face, so this offered a unique challenge. I was conscious of wanting to provide an equity of experience for the participants that were interviewed face to face, and those on the video calls. I learned that there is often a lot of non-verbal communication within an interview setting (e.g., nodding, gesture) that is more challenging when using video calls.

Some of the stories that I was told made me feel sad, and I joined some of the men in feeling stuck. I felt this most acutely on hearing participants' experiences with disclosure anxiety, and not feeling that they could tell others due to anticipating stigma. Throughout this research process I have been aware of my frustration at how HIV is constructed within society. Consequently, I have found myself having conversations with friends, family and colleagues about HIV because of my knowledge gained through conducting this research, which I hope will co-construct a new reality between us about HIV.

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A Ethics application result (July)

APPENDIX A. ETHICS APPLICATION RESULT (JULY)

Result of your application to the Research Ethics Co... - Gibson,...

<https://outlook.office.com/owa/?viewmodel=ReadMessageItem&...>

Result of your application to the Research Ethics Committee (application ID 60)

Ethics Application System <ethics@rhul.ac.uk>

Thu 14/07/2016 08:21

To: Gibson, Naomi (2014) <Naomi.Gibson.2014@live.rhul.ac.uk>; Evangeli, Michael <Michael.Evangeli@rhul.ac.uk>;
ethics@rhul.ac.uk <ethics@rhul.ac.uk>;

PI: Dr Michael Evangeli

Project title: Developing a model of the experience of individuals who have home tested as positive for HIV

REC ProjectID: 60

Your application has been approved by the Research Ethics Committee.

Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee
ethics@rhul.ac.uk

B Ethics application result (October)

APPENDIX B. ETHICS APPLICATION RESULT (OCTOBER)

Result of your application to the Research Ethics Co... - Gibson,...

<https://outlook.office.com/owa/?viewmodel=ReadMessageItem&...>

Result of your application to the Research Ethics Committee
(application ID 60)

Ethics Application System <ethics@rhul.ac.uk>

Fri 07/10/2016 09:31

To: Gibson, Naomi (2014) <Naomi.Gibson.2014@live.rhul.ac.uk>; Evangeli, Michael <Michael.Evangeli@rhul.ac.uk>;
ethics@rhul.ac.uk <ethics@rhul.ac.uk>;

PI: Dr Michael Evangeli

Project title: Developing a model of the experience of individuals who have home tested as positive for HIV

REC ProjectID: 60

Your application has been approved by the Research Ethics Committee.

Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee
ethics@rhul.ac.uk

C Participant information sheet



Participant Information Sheet



A study looking into the experiences of individuals who have self-tested positive for HIV

I, Naomi Gibson, Trainee Clinical Psychologist at Royal Holloway University of London, would like to invite you to take part in this research study. Joining the study is entirely up to you. Before you decide I would like you to understand why the research is being done and what it would involve for you.

This research is being undertaken as part of a Doctorate in Clinical Psychology, and is being supervised by Dr Michael Evangelis, Clinical Psychologist and Senior Lecturer at Royal Holloway, and Dr Michael Brady, Medical Director at the Terrence Higgins Trust.

Invitation and brief summary

I am conducting this study into the experiences of individuals who have self tested positive for HIV. Self testing for HIV is new, and we don't yet know how it affects people's wellbeing, and their care in the future. This study will contribute toward a doctoral study in Clinical Psychology, and it will be put forward for publication. Any identifiable details will be fully anonymised before any data is used for the doctoral thesis or publication.

You are being approached for this study because you have tested positive from a HIV self test. This study will be asking some questions about testing HIV positive from a HIV self test, you will also be given a questionnaire about your mood. You may have used a home test where you sent it away and wait for the results, or a home test where you see the results there and then.

What's involved?

If you choose to take part I will do a face-to-face interview with you. This interview will last approximately 1 hour and will be on one occasion. I will be asking you questions about your experience of self testing for HIV, and some of the experiences you have had following your HIV positive result from self testing.

Possible benefits of taking part?

It may feel helpful to talk about your experiences of using HIV self testing and finding out you are HIV positive. This study may also help others in the future. You may also find it helpful to take an active role in your own healthcare through the participation in research.

Possible disadvantages of taking part?

The interview will be asking you questions about your experience of finding out your HIV diagnosis by self testing. This could be a distressing process, or it might make you feel uncomfortable.

APPENDIX C. PARTICIPANT INFORMATION SHEET

I have many years experience of dealing with people who are distressed, and the interview can be stopped at any time you want if you do feel discomfort or distress.

Keeping you and your information safe

The interview will be taped onto a voice recorder, and all recordings will be deleted once they are written out using a computer. The information you give me will be anonymous and remain confidential; no identifiable details will be used in the write up of the doctoral thesis or any future publications. All data, including consent forms, demographic information and interview transcriptions, will be kept in a locked filing cabinet and/or password protected USB at Royal Holloway.

Participation in this study is voluntary and you are free to withdraw at any time without giving a reason, withdrawal does not affect your medical care or legal rights. I will also be asking you to sign a consent form separately to this participant information sheet.

The Royal Holloway college ethics committee has reviewed and approved this study.

The sites where the study will be conducted

The interview will be carried out in a private room in one of two central London locations:

- Terrance Higgins Trust offices, 314-320 Grays Inn Rd, WC1X 8DP
- Royal Holloway, University of London, 11 Bedford Square, London, WC1B 3RA

Skype interviews

The interview could also be carried out over a Skype video call if you live outside of London. Video calls using Skype are confidential and secure. The videos will not be saved anywhere; only the voice recordings will be saved using a separate voice recorder, as with the face-to-face interviews.

Expenses and payments

If you travel to the interview outside any normal appointment we will pay your travel expenses. You will also get paid a £10 amazon voucher for you time in taking part in the interview.

Contact details of researcher(s)

Naomi Gibson

naomi.gibson.2014@live.rhul.ac.uk

01784 414012 (please leave a message identifying your name and that you are leaving a message for Naomi Gibson)

Dr Michael Brady

michaelbrady@nhs.net

What if I have a complaint?

Please contact Dr Michael Brady on michaelbrady@nhs.net

D Consent form

APPENDIX D. CONSENT FORM



Participant Identification Number:

CONSENT FORM

Title of Project: **A study looking into the experiences of individuals who have self tested positive for HIV**

Name of Researcher: **Naomi Gibson**

Please tick box

- | | |
|--|--------------------------|
| 1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 3. I agree to having my interviews by Naomi Gibson audio recorded. | <input type="checkbox"/> |
| 4. I agree to having my anonymous quotes used in the write up of this study. | <input type="checkbox"/> |
| 5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. | <input type="checkbox"/> |
| 6. I agree to take part in the above study. | <input type="checkbox"/> |

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

E Interview schedule (version 1)

APPENDIX E. INTERVIEW SCHEDULE (VERSION 1)

Interview Guide

Questions followed by prompts

1.) Tell me a bit about yourself.

How do you spend your free time?

What sorts of things are you interested in?

What job do you do / what subjects do you study?

2.) What was your experience of HIV testing before you took the self-test at home?

How and when did you last test?

Going to clinic to test?

How often have you been testing for HIV in the past?

What was it that led you to be tested in the past?

3.) Can you tell me about your decision to take a home HIV test?

Why the self-test in particular?

What did you think/feel about the self-test?

Was this your first time testing in this way?

4.) What was your understanding of HIV testing before you took the home test?

What was your previous knowledge of HIV?

How much did you understand about HIV testing?

Was there anything that got in the way of HIV testing? (at the time of the self-test, or in the past?)

Were there any things that made it easier to home test?

5.) How did you feel about ordering the test?

What did you think/feel before it arrived?

How did you think/feel when it arrived?

Did you wait to take the test once it had arrived? How long?

6.) Can you tell me about your experience of taking the test at home

What were you thinking/feeling before taking the test?

What were you thinking/feeling during the test?

Did you feel like you were able to do the self-test on your own?

What were you thinking/feeling after completing the test?

Did you have any support from anybody else with the test- either practically emotionally?

APPENDIX E. INTERVIEW SCHEDULE (VERSION 1)

5.) What was your experience of finding out the positive result?

Where were you?

How did you think/feel?

Did you have any support?

Did you need any support if you didn't have any?

Did you receive any prompts from THT? What was it like to receive these text prompts?

6.) Can you remember what you did following the result?

What did you do straight away?

What did you do a week later?

How did you think?

How did you feel?

Did you tell THT straight away about the result or wait? Why?

What did it feel like receiving a text prompt from THT?

7.) Can you tell me about any important relationships with other people in your life at the time of the self-test?

Who did you tell about the result?

Did it have any affect on any important relationships? If so, how?

Did it affect your sexual relationships? If so, how?

8.) Can you tell me about your experience of going for a confirmatory test at a clinic following the test at home?

Did you wait before going for this test? If so, why?

Have you had any experience of taking medication/treatment, if so how is that for you?

What has professional support been like for you?

9.) Can you tell me about any important relationships with other people in your life at the moment?

Have you noticed any differences in your friendships since the diagnosis?

Have you noticed any differences in relationships with family since the diagnosis?

10.) Can you tell me about any sexual/intimate relationships in your life at the moment?

APPENDIX E. INTERVIEW SCHEDULE (VERSION 1)

Have there been any changes in your sexual relationships or choices since the diagnosis? If so, how?

Have you disclosed your HIV status to sexual partners?

Has this experience changed the way that you have sex?

11.) What's been your experience of sharing your HIV status?

Have you had any experiences of disclosing your HIV status? If so, what was this like?

Were there any barriers to disclosing?

What facilitated the disclosure/made it easier to disclose?

What made you choose to disclose (either at that time, or to that person?)

What was it like following the disclosure?

12.) In what ways has your life changed since your diagnosis?

What is it like living with HIV?

In what ways is your life the same?

Has it affected you in any ways that were unexpected?

13.) Having chosen to self-test, what advice would you give to someone else who is considering testing at home?

How does it compare with testing at the clinic?

How does it compare with any previous testing experiences you have had?

F Interview schedule (version 2)

APPENDIX F. INTERVIEW SCHEDULE (VERSION 2)

Interview Guide with amendments

Questions followed by prompts

1.) Tell me a bit about yourself.

How do you spend your free time?

What sorts of things are you interested in?

What job do you do / what subjects do you study?

2.) What was your experience of HIV testing before you took the self-test at home?

How and when did you last test?

Going to clinic to test?

How often have you been testing for HIV in the past?

What was it that led you to be tested in the past?

3.) Can you tell me about your decision to take a home HIV test?

Why the self-test in particular?

What did you think/feel about the self-test?

Was this your first time testing in this way?

4.) And what about HIV testing before you took the home test?

What did you think were the good things/benefits/bad things about testing when you tested before?

Was there anything that got in the way of HIV testing? (at the time of the self-test, or in the past?)

5.) What was your understanding of HIV testing before you took the home test?

What was your previous knowledge of HIV?

How much did you understand about HIV testing?

Were there any things that made it easier to home test?

6.) How did you feel about ordering the test?

What did you think/feel before it arrived?

How did you think/feel when it arrived?

Did you wait to take the test once it had arrived? How long?

7.) Can you tell me about your experience of taking the test at home

What were you thinking/feeling before taking the test?

APPENDIX F. INTERVIEW SCHEDULE (VERSION 2)

8.) What were you thinking/feeling during the test?

How confident do you feel in taking the test and managing the consequences before you took the test?

Did you feel like you were able to do the self-test on your own?

What were you thinking/feeling after completing the test?

Did you have any support from anybody else with the test- either practically emotionally?

9.) What was your experience of finding out the positive result?

Where were you?

How did you think/feel?

Did you have any support?

Did you need any support if you didn't have any?

Did you receive any prompts from THT? What was it like to receive these text prompts?

10.) Can you remember what you did following the result?

What did you do straight away?

What did you do a week later?

How did you think?

How did you feel?

Did you tell THT straight away about the result or wait? Why?

What did it feel like receiving a text prompt from THT?

11.) Can you tell me about any important relationships with other people in your life at the time of the reactive self test?

Who did you tell about the result?

Did it have any affect on any important relationships? If so, how?

Did it affect your sexual relationships? If so, how?

12.) Can you tell me about your experience of going for a confirmatory test at a clinic following the test at home?

Did you wait before going for this test? If so, why?

Have you had any experience of taking medication/treatment, if so how is that for you?

What has professional support been like for you?

APPENDIX F. INTERVIEW SCHEDULE (VERSION 2)

- 13.) Can you tell me about any important relationships with other people in your life at the moment?

Have you noticed any differences in your friendships since the diagnosis?
Have you noticed any differences in relationships with family since the diagnosis?

- 14.) Can you tell me about any sexual/intimate relationships in your life at the moment?

Have there been any changes in your sexual relationships or choices since the diagnosis? If so, how?
Have you disclosed your HIV status to sexual partners?
Has this experience changed the way that you have sex?

- 15.) What's been your experience of sharing your HIV status?

Have you had any experiences of disclosing your HIV status? If so, what was this like?
Were there any barriers to disclosing?
What facilitated the disclosure/made it easier to disclose?
What made you choose to disclose (either at that time, or to that person?)
What was it like following the disclosure?

- 16.) In what ways has your life changed since your diagnosis? In what ways is your life the same?

What is it like living with HIV?
Has it affected you in any ways that were unexpected?

- 17.) Having chosen to self-test, what advice would you give to someone else who is considering testing at home? (ask this earlier if appropriate)

How does it compare with testing at the clinic?
How does it compare with any previous testing experiences you have had?

G Service user feedback questions

Service User Feedback

Summary of the project

Naomi Gibson (a Trainee Clinical Psychologist at Royal Holloway, University of London) is carrying out a study exploring people's experiences of finding out they are HIV positive using a home HIV test.

Naomi aims to interview 10 people about what it was like to use a home HIV test, and what life has been like for them following their diagnosis. Participants will be recruited from Terrance Higgins Trust (a national HIV charity). Naomi will use the information from the study to write a thesis as part of a professional qualification to become a Clinical Psychologist.

How can you help?

Before conducting the interviews, it would be helpful to discuss the interview schedule with other people who have recently been diagnosed with HIV (at home or in a clinic). The interview is semi-structured. This means that the interview schedule is used as a "guide" to explore certain areas of interest however new ideas can be brought up during the interview based on what the interviewee says. The questions in bold will be asked first, followed up by the prompt questions (underneath) if appropriate. The order the questions are asked will be guided by the interviewees' responses.

Consider the following when looking at the interview schedule:

- **How each question is phrased**
 - **Are the questions clear / understandable?**
 - **Fair to ask?**
 - **Possible to answer?**
- **Questions to add / other areas to cover.**
- **Questions to remove.**
- **Any other comments?**

H Demographic information questionnaire

APPENDIX H. DEMOGRAPHIC INFORMATION QUESTIONNAIRE



Demographic information questionnaire



Gender:	
Age:	
Country of birth:	
If not born in the UK, how long have you been living in the UK?	
Ethnicity:	Asian, Indian ____ Asian, Pakistani ____ Asian, Bangladeshi ____ Asian, any other ____ Black, Caribbean ____ Black, African ____ Black, any other ____ Mixed, White and Black Caribbean ____ Mixed, White and Black African ____ Mixed, White and Asian ____ Mixed, any other ____ Chinese ____ White, British ____ White, Irish ____ White, any other ____ Any other ____ Rather not say ____
Relationship status- are you currently:	Married/living with partner ____ In a relationship (not living together) ____ Single ____
Sexuality:	
Occupational status:	
What form of HIV home test did you use?	Self test (blood prick test yourself at home with results immediately) ____ Self sample test (saliva or blood prick test yourself at home sent to a lab for results) ____
When did you take the home HIV test?	
How many times have you taken a home HIV test	

APPENDIX H. DEMOGRAPHIC INFORMATION QUESTIONNAIRE

before?	
How many times have you been tested for HIV in any other format before? eg. at a sexual health clinic, at your GP.	
CD4 count at diagnosis (if known):	
Current viral load (if known):	
Are you on ART medication?	

I Hospital anxiety depression scale questionnaire

APPENDIX I. HOSPITAL ANXIETY DEPRESSION SCALE QUESTIONNAIRE



Mood questionnaire- HADS



Please choose one response from the four given below. Please give your immediate response without thinking too long about your answer.

A	I feel tense or 'wound up':	
	Most of the time	3
	A lot of the time	2
	From time to time, occasionally	1
	Not at all	0

D	I still enjoy the things I used to enjoy:	
	Definitely as much	0
	Not quite so much	1
	Only a little	2
	Hardly at all	3

A	I get a sort of frightened feeling as if something awful is about to happen:	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0

D	I can laugh and see the funny side of things:	
	As much as I always could	0
	Not quite so much now	1

APPENDIX I. HOSPITAL ANXIETY DEPRESSION SCALE QUESTIONNAIRE

	Definitely not so much now	2
	Not at all	3

A	Worrying thoughts go through my mind:	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0

D	I feel cheerful:	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0

A	I can sit at ease and feel relaxed:	
	Definitely	0
	Usually	1
	Not Often	2
	Not at all	3

D	I feel as if I am slowed down:	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0

APPENDIX I. HOSPITAL ANXIETY DEPRESSION SCALE QUESTIONNAIRE

A	I get a sort of frightened feeling like 'butterflies' in the stomach:	
	Not at all	0
	Occasionally	1
	Quite Often	2
	Very Often	3

D	I have lost interest in my appearance:	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0

A	I feel restless as I have to be on the move:	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0

D	I look forward with enjoyment to things:	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3

APPENDIX I. HOSPITAL ANXIETY DEPRESSION SCALE QUESTIONNAIRE

A	I get sudden feelings of panic:	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0

D	I can enjoy a good book or radio or TV program:	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

J Receipt of payment for interview

APPENDIX J. RECEIPT OF PAYMENT FOR INTERVIEW




Receipt of payment for interview

I can confirm that I have received **£10 (cash or amazon voucher)** from Naomi Gibson for taking part in the study looking into the experiences of individuals who have self tested positive for HIV.

Plus expenses for travel to interview _____

Signed participant:

Signed researcher: 

Date:

K Research memos

Example researcher memos

19/01/2017

Is there something about sex becoming less appealing after testing positive?

Either because the chase may have gone (pt 4) or because of the way it is making you feel about yourself (pt 2)?

Hypothesis: The importance that the men are placing on sex, and sexual relationships and their selves.

Hypothesis: Is getting back to sex “business as usual” part of good adjustment, and therefore without it there is a struggle to adjust?

24/01/2017

Is there a difference in the readiness to take the self-test? Not necessarily why they chose it (practically) but how ready they felt.

PT 5 who had already attempted the self-sampling at home then saw the advert once or twice on Grindr before ordering. Compared to pt 4 who was unsure what to do, much more ambivalent and less ready to know his HIV status, he had to see the advert several times and it was “playing on his mind” before placing the order.

Question for analysis: Does ambivalence and readiness to self-test affect adjustment to diagnosis?

26/01/2017

Avoidance of thinking about it too much until the confirmatory test? E.g. take the test and then don’t think again about it. Shock, denial of self-test and initial self-test.

APPENDIX K. RESEARCHER MEMOS

Believing it enough to get tested (e.g. there's a reason why they ordered the self-test/are testing for HIV) but then when the result comes from the self-test needing that to be confirmed to feel 100%. "Having it done properly" (pt 5)

That being the catalyst then to exploring more feelings, feelings "n hold' for some people until then (pt 5)

Question for analysis: Is denial a focused code?

Question for analysis: Shock

Hypothesis: Participants wanting to feel 100% sure as soon as possible as well. Within minutes, hours. They know what to do after self-testing.

L Reflective diary

Extracts from the researcher's reflective diary

27/10/2016

The skype interview was with a man with a very different temperament to the face-to-face interview in the morning. He appeared quiet and reserved, and worked a job where he was mostly alone throughout the day.

I felt apprehensive about the format of the first Skype interview, mostly because I was unsure whether the technology was going to in some ways fail me, and my recordings would not record well. This didn't happen, and I felt like it was a close interview experience, much like the one in the morning had been.

The participant had some grievances with the way that things had been for him and his treatment journey. I found myself in some ways wanting to know more, and in some ways wanting to protect the NHS and present my employer in a positive light. This was an interesting dichotomy, and I reflected on the unique position on being a NHS clinician and having insights and understanding in to the running of the system that he was understandably frustrated with.

I was struck by how easy both participants felt that it had been to administer the self-test. It made me reflect that I did have pre-conceived ideas that it would be difficult to administer, or that it might, in some ways, be the practical aspects of the testing that participants would report to me. For these two, the actual test itself seemed very straightforward.

APPENDIX L. REFLECTIVE DIARY

04/11/2016

Face to face interview, older than the other participants (mid 50's). He spoke frankly about his sexual risk taking, I felt unsure if this frankness came from being older or from taking greater sexual risks than others. He also appeared to be visually anxious (e.g. fidgeting, restless) which made the interview trickier to conduct, and to keep on track. He described himself as having long standing anxiety, seemed to be anxious in his descriptions of things and the process was jumping around, often not sticking to the questions asked. I wondered during the interview and afterwards if I was responsive enough as a researcher? I felt as though his experience was particularly unique (e.g. admittance to hospital, self-awareness of risky sexual behaviour) but I am not sure if I explored this in enough depth to see whether it relates to any of the other participants.

On ending the interview, and turning off the recorder he asked me for some advice about disclosing his HIV status on dating sites (e.g. how to say it, what to say). I was struck by his slightly defensive way of talking about dating and disclosure to others (e.g. "they should know I've got HIV and will either accept me or not, it's their problem"). Also, I found it difficult to answer in my role as a researcher psychologist, having only met him for a brief amount of time and I didn't feel able give him advice. I ended up speaking about the available support services through THT such as groups, befrienders that would be able to talk to him about these legitimate concerns and think through these with him.

11/11/2016

APPENDIX L. REFLECTIVE DIARY

Had a very pleasant face-to-face interview on a Friday afternoon with this young, black man. He appeared to be at times at ease with his narrative and diagnosis, and then at others visibly anxious and ill at ease.

Speaking with him gave me important insight into the gay community in London including his awareness of stigma e.g. "if you tell people they won't want to have sex with you"... "pos/neg on dating apps". It would be good to check these perceived stigmas out with other participants if appropriate in interviews.

During our conversation, I wondered how much he could share his thoughts and concerns with me, especially as many of them were highly relevant to his life as a gay man. I felt comfortable to talk to him about sex, from my clinical experience of doing this with many gay and heterosexual clients however he may not have spoken with anyone other than friends or partners about sex before. I wonder if I should have given a brief disclaimer at the start of the interview e.g. "there will be questions about lots of different things including sex", as it was during this part of the interview that he appeared most visibly anxious in his seat.

M Example transcript with initial and focused coding

APPENDIX M. EXAMPLE TRANSCRIPT WITH INITIAL AND FOCUSED CODING

Transcription	Initial codes	Focused codes
PT 2: And more likely... points of infection than anything else really	Knowing the points of infection	
I: Yeah		
PT 2: But because it's only really <u>since</u> been diagnosed that I've learnt, a lot more but in a lot more detail what it all means and...	Learning more in detail since diagnosis Not knowing as much about HIV before he was diagnosed	Needing to educate self and others
I: Mmmhmm		
PT 2: how it all happens	Learning	
I: Ok		
PT 2: And how to collect		
I: Ok, so just to just go back just a bit... how, what was your experience like of actually taking the test at home? You said that, you know, it was similar to when you took the test before but can you remember what you were thinking and sort of feeling when you were taking the test?		
PT 2: Yeah, it's, I always end up – I don't quite know why – but I always end up doing it in the, kitchen, I don't quite know why	Remembering taking the test Always taking test the same way Doing the test in the kitchen at home Feeling unsure	Feelings before and during the self-test
I: In the kitchen, did you say?		
PT 2: Yeah		
I: Yeah		
PT 2: And because once you're when you're kind of doing it it's the whole, there's a slight apprehension when obviously, you have to use a lancet on your finger and that kind of stuff	Feeling slightly apprehensive when using a lancet on his finger Anxiety	Feelings before and during the self-test
I: Mmmhmm		
PT 2: Which again doesn't bother me but you've kind of got that... when you go to do it there is that kind of fight or flight thing about doing it and you kind of hesitate when you when you go to prick	Feeling generally unbothered by lancing his finger Describing anxiety	Feelings before and during the self-test

APPENDIX M. EXAMPLE TRANSCRIPT WITH INITIAL AND FOCUSED CODING

your finger and that kind of stuff	Experiencing “fight or flight” before pricking the finger Hesitating	
I: Mmm		
PT 2: So, I always end up having that, just for a split second and then you just kind of cave in and do it	Feeling momentarily unsure Going ahead with the test	Feelings before and during the self-test
I: Yeah		
PT 2: I remember doing that same as I always do and setting the test up, because once you’ve kind of got it ready you then have it standing upright	Remembering doing the same as with previous tests in the past Setting the test kit up beforehand Knowledge of previous testing	Feelings before and during the self-test
I: Mmmhmm		
PT 2: and one of the things that part of the instructions of the test is to check it after a few minutes to make sure it’s working	Checking the test after a few minutes to check its working	Feelings of doubt and uncertainty at the self-test result
I: Ok		
PT 2: And it... and they give you, obviously, they give you some information that are things to look for to see that it is definitely working	Knowing what to look for on the test kit to check it was working Seeing test is working	
I: Mmmhmm		
PT 2: And I’d kind of done it and put the plaster on my finger and kind of set it up and everything and I kind of looked at it and that was when after a few minutes, I saw the liquid is going up the middle of the test	Finishing test Looking at the test Seeing the liquid going up in the middle of the test	
I: Mmmhmm		
PT 2: And that was when I saw one of the lines across the middle	Seeing one of the lines across the middle of the test	
I: Ok		
PT 2: And when I looked at it I thought: that’s a little bit low to be the control line	Feeling confused Thinking that line is a bit low to be the control line	Feelings of doubt and uncertainty at the self-test result

APPENDIX M. EXAMPLE TRANSCRIPT WITH INITIAL AND FOCUSED CODING

I: Mmm			
PT 2: That looks a little bit too far down the test to be the control	Thinking that the line could not be the control line		
I: Mmmhmm			
PT 2: And I kind of thought: really, it's still not had its 15 minutes yet. And I deliberately came and sat in the living room and put the telly on, and I think I just made a kind of a conscious effort to forget about it	Reassuring self Deliberately leaving the test kit alone Trying to forget about the test	Feelings of doubt and uncertainty at the self-test result	
I: Mmmhmm			
PT 2: Because I think maybe kind of psychologically I knew that it was too low to be the control line and therefore it was gonna come back positive	Being aware the test might be positive		
I: Ok			
PT 2: I kind of forgot about it and I left it probably about 25 minutes in the end	Noting then leaving the test for about 25minutes Forgetting the test		
I: Ok			
PT 2: And it was only when I went back to it that I saw both lines on the test and I thought: yeah, I was kind of expecting that	Returning to the test to see that it had both lines Thinking that to see the two lines on the test was expected at that point	Feelings before and during the self-test	
I: So, you stepped away from it?			
PT 2: Yeah			
I: You were able to kind of distract yourself a little bit with the telly or with...?			
PT 2: Yeah it kind of like, I think at that point when I saw it and realised that the control, the line that was showing was too...it was quite tricky, too fine, at the bottom of the bottom of the test to be the control line for it	Being aware early that it was positive Realising at the beginning of the test that he might be HIV positive	Feelings before and during the self-test	
I: Mmm			

APPENDIX M. EXAMPLE TRANSCRIPT WITH INITIAL AND FOCUSED CODING

PT 2: And I think it was at that point, it was only a few minutes into the test and I kind of thought yeah, I can, I'm gonna leave it because its gotta run for 15 minutes anyway I: Mmmhmm	Thinking he wanted to leave the test to run for 15 minutes	
PT 2: And I kind of I think I kind of very deliberately became kind of ignorant to it and I just kind of forgot about it I: Mmm	Making a deliberate intention to ignore the test Avoidance	
PT 2: to deliberately go and do something else I: Mmm	Distracting self Attempting to manage feelings	Feelings before and during the self-test
PT 2: And that was why I realised at the end of the programme I was watching: I left it like 25 minutes I: Ok	Leaving test for 25minutes	
PT 2: So, I thought: Ok, yeah, it's definitely done now I: Ok	Thinking that test would've then been done	
PT 2: Go and have a look at it I: Ok. And were you on your own when you were taking the test?	Going to look at the test	
PT 2: Yeah I: Yeah, and so when you went back to the kitchen were you on your own then?	Taking the test on his own	Being alone to self-test
PT 2: Yep I: To have a look at it. So, what was that like, having a look at that result and finding out that it was a reactive test then. How was that experience?	Finding out the positive result on his own	Being alone to self-test
PT 2: It's... I kind of <u>knew</u> that kind of walking up to, you know, kind of back into the kitchen and seeing it kind of standing there and seeing both lines very clearly. I think because I kind of	Returning to the kitchen and seeing both lines very clearly Having a subconscious awareness of	Feelings before and during the self-test

APPENDIX M. EXAMPLE TRANSCRIPT WITH INITIAL AND FOCUSED CODING

subconsciously was kind of aware of it, you know, it was kind of like, kind of took a bit of a deep breath and thought; oh ok, great, awesome	the positive result Taking a deep breath Realisation	
I: Mmm		
PT 2: You know, I know they're not 100% accurate, they're 99.7% accurate	Thinking about the possible inaccuracy of the test kits Reassuring self Disbelief	Feelings of doubt and uncertainty at the self-test result
I: Yeah		
PT 2: But, I had thought it did come back with that positive line very, quickly, into the test, before I obviously walked away from it anyway so I think I just kind of, I guess I just kind of took a deep breath really and just kind of looked at it, and you kind of stir it into the kit, so you can compare it, with, like a chart on the side	Remembering the speed of the positive line within the testing Checking the test kit	Feelings of doubt and uncertainty at the self-test result
I: Mmmhmm		
PT 2: The inside of the box, so you can see where the lines line up for a control line or a positive test result	Going back to test instructions	
I: Ok		
PT 2: I kind of did that, not really needing to by that point	Confirming the result using the test kit instructions Being aware that it may not be needed at that point	
I: Mmmhmm		
PT 2: But I mean it did it anyway just to be 100% certain, to see it. It was kind of like: oh, ok, awesome, great, ok, kind of need to go and get that confirmed, really don't I?	Wanting to be 100% certain Thinking that he needed to go and get the test confirmed Knowing what to do	Knowing what to do immediately after self-testing
I: Yeah		
PT 2: And I was kind of...		
I: Yeah		

APPENDIX M. EXAMPLE TRANSCRIPT WITH INITIAL AND FOCUSED CODING

<p>PT 2: I told myself, you know, it's pretty accurate but at the same time, it could still be wrong. It could be a false positive so if it's just a case of yeah</p>	<p>Telling self that it is accurate Thinking test could be wrong Thinking that it could be a false positive Being aware of what to do Anxiety</p>	<p>Knowing what to do immediately after self-testing</p>
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